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ABSTRACT

Interviews were conducted with parents of mentally retarded youth who had completed their education at special education centers or in Educable Mentally Retarded classes within regular high schools of the Allegheny Intermediate Unit (Pennsylvania). Students included 72 individuals who left the special education centers in 1987 (1-year follow-up); 19 individuals who left in 1986 (2-year follow-up); and 30 individuals who had completed regular school in 1987. Findings are presented by exceptionality group: severely/profoundly mentally retarded, trainable mentally retarded, and educable mentally retarded. Individuals' vocational situations and living arrangements are discussed, along with reasons for lack of work activity, parents' preference for youngsters' living arrangements and eventual employment situation, relationship of present situation to in-school vocational training, and relationship of number of parents to employment status. It is concluded that: (1) an extremely high percent of youngsters live with their parents and guardians after completing school; (2) a great deal still needs to be done to create satisfactory vocational outcomes for mentally retarded youngsters who have completed school; and (3) mentally retarded youngsters from one-parent families are less likely than those from two-parent families to be working 1 year after completing school. (JDD)

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MENTALLY RETARDED YOUTH IN TRANSITION: FOLLOW-UP ONE AND TWO YEARS POST-SCHOOL

by

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Mentally Retarded Youth in Transition: Follow-up One and Two Years Post School

EXECUTIVE SUMMARY

This year's work continues the follow-up of 1985-1986 MR school completers of the AIU's special education centers begun last year. This year we contacted the parents and guardians of the 1986-1987 cohort of completers, both center-based and mainstreamed, to determine their situations one-year after completing school. We also reinterviewed the parents of the 1985-86 cohort to investigate their lives two years after leaving school. The report presents conclusions and issues based on study outcomes, and detailed findings from both studies for all groups researched. These include living and work situations, parent attitudes, vocational training, and the results of investigations into relationships between variables.

CONCLUSIONS AND ISSUES

Conclusion I: An extremely high percent of youngsters live with their parents and guardians after completing school.

Issue 1: The arrangement in which mentally retarded adults live indefinitely with their parents is costly to the mentally retarded adult, the parents, and other family members.

Issue 2: The arrangement in which a mentally retarded adult remains in the family home cannot be maintained for the life of the adult child.

Proposed action steps: research, assistance for families who prefer alternative housing arrangements, and working with parents to expose them to other options.

Conclusion II: A great deal still needs to be done to create satisfactory vocational outcomes for mentally retarded youngsters who have completed school.

Issue 1: Vocational options that parents are accepting for their children, which do not involve competitive employment, are not congruent with state-of-the-art goals.

Issue 2: Differing views by parents and professionals of appropriate goals for MR youngsters have lead to misunderstanding and decreased opportunities for young people.

Issue 3: Potential loss of benefits and disposable income act as disincentives to full-time competitive work.

Suggested action steps include: parent training, increasing

professional sensitivity to parent concerns, in-school supported work and the establishment of clear guidelines for eligibility for benefits.

FOLLOW-UP OF 1986-1987 SCHOOL COMPLETERS

* 31% of SPMR completers, 87% of TMR completers and 86% of EMR completers live at home one year after leaving school.

* The most common outcomes for TMR youngsters after one-year are: no activity (40%), activities center (29%), and sheltered workshop (23%).

* The primary in-school vocational experience of TMR youngsters is WAC. All 1986-1987 TMR completers had WAC experience, 72% for 3 or more years.

* For all EMR completers: 34% are idle one year after leaving school, 49% are working.

* Restaurants are the most frequent work settings for EMRs.

TWO-YEAR FOLLOW-UP OF 1985-1986 SCHOOL COMPLETERS

* 81% of the both TMR and EMR youngsters live with parents or guardians two years after leaving school.

* Activities center remains the most frequent placement for TMR youngsters after two years. 41% of TMRs were in these centers, 22% each were in sheltered workshops and idle.

* 65% of the EMR group was employed two years after completing school, 23% was idle.

* There was no relationship between parents' feelings about the future and youngster's vocational situation. Some parents with youngsters in TACS and sheltered workshops feel good about these situations and some are discouraged. Those whose youngsters were not working for two years tend be more discouraged.

ADDITIONAL VARIABLES AND RELATIONSHIPS EXPLORED

Reasons Given for Lack of Work Activity

* The most frequent reasons parents of TMR youngsters gave for their not having a work-related activity were: youngster's attitude and/or behavior, transportation problems, and the need for more training.

* The three most frequent reasons given for the total EMR group were: youngster's attitude or behavior, disability prevents work, and married/pregnancy/raising children. The reasons given for mainstreamed and center completers differ.

Parent's Preference for Youngster's Eventual Employment Situation as it Relates to Present Situation

* Parents of those youngsters currently in an activity most frequently prefer that situation. This preference increases as the situation moves toward competitive work.

* Those parents who do not prefer the status quo, prefer higher level placements for their youngsters. 3/4 of the parents of youngsters who are idle would like to see them in some placement.

* Parents of TMRs youngsters indicate less interest in competitive employment. Two years after their leaving school, half the parents of idle youngsters prefer non-work options. 44% of the parents of youngsters in activity centers prefer that situation.

Parents' Preference for Youngsters' Living Arrangement

* 67% of the parents of all non-SPMR center completers whose youngsters live with them prefer them to remain at home.

* 80% of parents of TMR youngsters express this preference. Only 38% of parents of mainstreamed youngsters prefer them at home.

* Parent preference for youngsters living with them appears not to diminish after two years.

Relationship of Present Situation to In-School Vocational Training

* Center-based EMRs who had had coop and/or AVTS experience were more likely to be employed one-year post-school than those who had not had these experiences.

* The higher the level of vocational training of second-year EMRs, the higher the likelihood of being employed.

* Since it is more able youngsters who reach higher levels of training, it is likely that a combination of both enhances vocational potential.

Relationship of Number of Parents to Employment Status

* 1987 EMR completers who come from 2-parent families are more likely to be employed than those from one-parent families.

* A number of hypotheses to explain this finding were not testable with the present data, but may suggest directions for further research.

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INTRODUCTION

The 1988 HWPA/CRA project sponsored by the Edith L. Trees Charitable Trust has enriched our study of mentally retarded youth in a number of ways. In 1987 we began our follow-up study by interviewing the parents of youngsters who had completed their educations at the six special education centers of the Allegheny Intermediate Unit (AIU) in the 1985-1986 school year. This year's work strengthened and deepened that study by focusing on a number of elements:

1) Follow-up study of 1986-1987 school completers: This year we continued our study of youngsters one year after completing school by interviewing the parents of youngsters who had completed their educations in the 1986-1987 school year. Also, an additional element was added to the previous year's group. This year, not only did we study youngsters who had attended the six special education centers, we also looked at another group about which we had long been curious. We also interviewed the parents of youngsters who had completed their educations as mainstreamed students; those who had been in EMR classes under the auspices of the AIU within regular high schools. These youngsters are generally somewhat less handicapped than those in special education centers, were judged better able to integrate into a non-special education environment, and/or felt (or whose parents felt) a strong preference for a mainstreamed setting. We were quite pleased to have been able to include a cohort of these students in the 1988 study.

This year's study then, enhances our picture of the one-year situation of MR students three-fold. Together with last year's results, we now have three groups which give us information on the fate of MR students one-year after school completion: the 1985-86 special education center cohort, the 1986-87 special education center cohort, and the 1986-1987 mainstreamed cohort.

2) Two-year follow-up of the 1985-1986 cohort. 1988 research also included re-contacting the parents of the 1985-1986 completers. We interviewed these parents about their youngsters' present work and living arrangements, training involvement, and reasons for not working. We also asked for their preferences regarding their youngsters' eventual work and living arrangements. In addition, by asking whether they felt more discouraged/about the same/more encouraged in terms of their youngsters' future, and why, we elicited telling comments about their lives with their youngsters. Following the same group for two-years has given us the power of a longitudinal study: we are able to examine work status, living arrangement, parental attitudes, etc., over a 2-year period, observing shifts and

changes. By gathering information on the youngsters' school careers, their lives one-year after school completion, and their lives two-years after school completion, we have become acquainted with them in a meaningful way. We have a sense of really getting to know a group of youngsters, to have gained insight into their lives, and an indication of what their futures may hold. Parents' feelings about their lives with their mentally retarded sons and daughters will be included in this section of the report.

3) Development of a tracking system. The importance of follow-up of handicapped students is becoming recognized around the country. As the first groups of handicapped youngsters who have benefitted from full education leave school, the question becomes, what is next for them? What kind of future lies in store for these youngsters? Are the post-school systems adequate to meet their needs? What additional supports or programs are needed? Are the school programs preparing these youngsters adequately? Which school programs seem better able to do so? New questions have also entered the picture: What can be expected for these youngsters? What are successful outcomes? As is being recognized around the country, these questions can only be answered by following youngsters after they complete school. This year, we have developed a computerized system to track school completers. It involves periodic re-contact with youngsters/parents after school is completed, determining youngsters' situations at each point of contact. It is a computerized system which, with modification, personnel training and technical assistance, can be put into place within a school system. The tracking system will be reported in a separate volume.

The following report will first present a summary of the research, which can be used by the reader to obtain an overview of study methodology and results. Second will be a discussion of conclusions drawn from the study findings, related issues, and proposed action steps. Study Section I will then discuss the follow-up study of 1986-1987 school completers, drawing on findings from the three one-year cohorts. Study Section II covers the two-year follow-up of the 1985-1986 cohort. Finally, Study Section III will focus on a number of variables and relationships which were explored using the findings of both the one- and two-year studies.

SUMMARY OF FINDINGS

FOLLOW-UP OF 1986-1987 SCHOOL COMPLETERS

This year's work continues the follow-up of 1985-1986 MR school completers of the AIU's special education centers begun last year. In this year's research, we contacted the parents and guardians of the 1986-1987 cohort of completers, to determine their situations one-year after completing school. The study sample included both youngsters who had been educated at the centers, and those who had been mainstreamed in EMR classes under AIU auspices in area high schools.

Findings for the one-year follow-up are presented by exceptionality group: SPMR, TMR and EMR. Where appropriate, findings from last year's cohort will be cited to permit the most complete picture of the youngsters' situations one year post-school. For the EMR group, three groups of one-year results will be presented: those for the 1985-86 cohort, the 1986-1987 center cohort, and the 1986-1987 mainstreamed cohort.

The SPMR Group

* Half of the SPMR completers from this year's study, and 19% of those from last year's, live with parents or guardians. The remainder live in institutions or group settings.

* 4 out of 10 1986-1987 completers attend Therapeutic Activity Centers (TACs).

The TMR Group

* 87% of TMRs completing school in 1985-1986 and 1986-1987 live at home one year later.

* The 1987 completers were almost evenly divided between those with no activity (52%) and those in activity centers and sheltered workshops (48%). A higher percentage have no activity in this year's cohort than last year's (52% vs. 30%). A lower percent are in sheltered workshops or activity centers (48% vrs. 56%). Unlike last year, no TMR individual was competitively employed this year.

* For the total group, including both years' cohorts, the most common outcome after one-year was no activity (40%), next was activities center (29%) and, then, sheltered workshop (23%).

* The primary in-school vocational experience of TMR youngsters is Work Activity Centers (WACs). All of the

1986-1987 TMR completers had been in WACs; 72% for 3 or more years. WAC was the only in-school vocational experience for 56% of the group.

* 9 TMR youngsters took vocational courses at their special education centers in subjects such as food service, auto mechanics and buildings/grounds maintenance. Two had co-op job placements.

The EMR Group

* The overwhelming majority of the EMR completers also live with a parent or guardian one year after school: 88% of this year's center completers, 89% of last year's center completers and 80% of the mainstreamed completers.

* 6 of this year's mainstream subjects (20%) and 3 (10%) of the center completers are living independently, either alone, with a spouse, or with a roommate. One center completer is in an institution.

* 52% who completed school in 1986-1987 are engaged in competitive employment or supported work; 57% of the mainstreamed completers and 38% of the center completers.

* One-third of all EMR completers are not involved in work or training activity of any kind; 27% of mainstreamed completers and 38% of center completers. 5 individuals who had been mainstreamed (17%) are in post-school training. 4 from the centers (12%) are in sheltered workshops or activity centers.

* Considering all three groups, about a third (34%) of EMR completers have no work-related activity one year after leaving school, almost half (49%) are in regular or supported work, and 8% each are in activities centers or workshops, and in training. Center completers are more likely to be no activity, and less likely to be competitively/supportively employed, than mainstreamed completers.

* Restaurant/food service institutions are the most frequent work settings for employed EMRs. 42% of the employed EMRs from all cohorts are employed in restaurants, fast food outlets or sandwich shops.

* Other jobs in which this year's EMR workers are employed include: janitors, laborers, meat cutter, nurses aide and stock clerk.

* Center and mainstream workers use different routes to obtain work. 69% of center workers from the 1986-1987 cohort were referred to their jobs either by their school or by a social service agency. 58% of mainstream workers found their jobs

through friends or family members or by applying on their own.

* 53% of workers from the mainstream group, and 62% of those from the centers (55% of all EMR workers from the 1986-1987 study year), are working less than full-time. All but two earn more than minimum wage.

* Half of the mainstreamed EMRs and nearly three-fourths (74%) of those from centers in the 1986-1987 cohort, took vocational courses at a special education center. Food Service and Building/Grounds Maintenance were especially popular, although a variety of courses were taken by both groups. 38% of center EMRs participated in WACs at their schools.

* 47% of mainstream completers, and 21% of center completers, took courses at AVTSs. Mainstreamed AVTS students took courses in 10 different subject areas, those from centers were concentrated in a few areas.

* 20 of the 34 center EMRs (59%) participated in co-operative education in 9 different types of work settings. Only 7 (23%) of the mainstream youngsters were involved in co-op. The most frequent co-op setting, for 23%, was a restaurant.

* In-school vocational experience differs for center-based and mainstreamed EMR students. Center-based students were particularly involved in courses in their own schools and in co-op placements. Some participated in WACs in their centers, and a smaller number attended AVTSs. Mainstreamed students tended to take courses at the special centers and at the AVTSs. Fewer participated in co-op jobs. 23% of mainstreamed students and 6% of center students had no in-school vocational training.

TWO YEAR FOLLOW-UP OF 1985-1986 SCHOOL COMPLETERS

The second major aspect of the 1988 Trees study involved re-contacting the parents/guardians of the youngsters who had completed school in the 1985-86 school year. These individuals had been interviewed last year as to the status of their youngsters one year after leaving school. This year's study informed us of these youngsters' situation two years after leaving school. The methodology of this study was basically the same as that of the one-year follow-up.

The SPMR Group

* The living arrangements of the SPMR subjects who have been out of school for two years are: 3 live with parents or guardians, 3 in group settings and 13 in institutions. All but 3 of the institutionalized youngsters participate in

activity centers of some kind.

* All 3 parents whose youngsters live with them would prefer to have their youngster remain at home. 2 of the 3 however, are beginning to consider the possibility of alternative settings such as group homes or CLAs. Of the 5 parents in the one-year cohort whose SPMR youngster lives with them, 4 state that they prefer their youngster to remain with them.

The TMR Group

* 81% of the TMR completers were living with their parents for both years of the study. In 1988, there was one youngster living alone, 2 in group settings and 2 in institutions.

* Activities center, which includes Therapeutic Activity Center (TAC), a nonvocational setting, as well as Work Activities Center (WAC), remains the most frequent placement for TMR youngsters both years. In 1988, 41% of TMRs out of school two years were in these centers, 22% each were in sheltered workshops and idle.

* Exploring parental attitudes towards youngsters' futures, it was found that 45% feel more discouraged or have about the same negative view they had had while the youngster was in school and 30% feel more encouraged about their youngster's future or have about the same positive view as they had had while he/she was in school.

* There was no relationship between feelings about the future and youngster's vocational situation. Some parents with youngsters in TACS and sheltered workshops for at least two years felt good about these situations and some were discouraged, feeling that no improvement was evident. Those whose youngsters were idle at both year's interviews expressed either about the same negative view or were more discouraged.

The EMR Group

* 81% of the EMR youngsters live with parents or guardians two years after leaving school. Two individuals live with spouses, one with children, one with a roommate, and one is in the Navy.

* The only change in the living arrangements of this cohort from the first year out of school to the second, is that two youngsters who lived with parents/guardians last year now live with spouses.

* 65% of the group was employed two years after completing school, 23% was idle, 8% in activities centers and 4% in sheltered workshops. More of the EMRs were working, and fewer were idle, than at last year's interview. 4 who were

idle, and 2 who were in training, are now employed. One who was employed is now idle.

* 50% of these youngsters parents or guardians state that they feel more discouraged about their youngster's future, or have about the same negative view as they had had while he/she was in school. 42% feel more encouraged or have about the same positive view they had had while the youngster was in school.

* There was no relationship between feelings about the future and present vocational situation. Some parents whose youngsters have been working or in training for at least two years feel encouraged by this, and some discouraged, feeling they want more for their youngster. Some with youngsters in activity centers and sheltered workshops both years are satisfied with this placement. Those whose youngsters have not been working for two years describe themselves as more discouraged, and some feel additional training or assessment is needed, which they have not been able to arrange.

ADDITIONAL VARIABLES AND RELATIONSHIPS EXPLORED

This section of the report focuses on three variables: the reasons parents of unemployed youngsters gave for their lack of work activity, parents' preferences for youngsters' eventual employment situation, as it relates to their present placement, and parents' preferences for youngsters' eventual living situation, for those parents whose youngsters currently live with them. It then turns to a number of relationships: that of in-school vocational training to vocational situation, and number of parents to vocational situation. Results discussed in this section are drawn from the one-year follow-up and, where indicated, the two-year follow-up.

Reasons Given for Lack of Work Activity

* The most frequent reasons parents of TMR youngsters gave for their not having a work-related activity were: youngster's attitude and/or behavior, transportation problems, and the need for more training.

* The three most frequent reasons given for the total EMR group were: youngster's attitude or behavior, primary or secondary disability prevents work, and married/pregnancy/raising children.

* The reasons given for mainstreamed and center completers not working differ. The most frequent reason given for lack of activity of mainstreamed youngsters, is married/pregnancy/raising children, followed by attitude or behavior, needs more training, and cannot handle work situation. Center youngsters are most frequently described

as not working because of their attitude and behavior, their primary or secondary disability, transportation problems and problems with the system.

Parent's Preference for Youngster's Eventual Employment Situation as it Relates to Present Situation

One-year follow-up:

* The responses of all the parents interviewed after their youngsters were out of school one year, excluding those of parents of SPMR youngsters, indicate that parents prefer vocationally-oriented activity for their youngsters, and prefer placements that more closely reflect real work.

* Parents of those youngsters currently in an activity most frequently prefer that situation. The strength of this preference increases as the situation moves toward competitive work: 42% of parents of youngsters in activities centers, 56% of those in sheltered workshops, and 83% of those in competitive employment prefer the status quo.

* Those parents who do not prefer the status quo, prefer higher level placements for their youngsters. 44% of parents of youngsters in sheltered workshops would like to see them in competitive or supported employment. 53% of parents of youngsters in activity centers would prefer their youngsters to be in competitive or supported employment, or in sheltered workshops.

* 3/4 of the parents of youngsters who are not working or involved in any vocationally-oriented placement would like to see their youngsters in such a placement. They also strongly prefer real work over activity centers or sheltered workshops.

* Parents of TMRs youngsters indicate less interest in competitive employment.

Two-year follow-up:

* The parents of youngsters in competitive or supported employment in the second year of follow-up all prefer competitive work for their youngster. Those parents whose youngsters are not involved in any vocational placement the second year also strongly prefer competitive or supported employment. The parents of youngsters in activities centers and sheltered workshops tend to prefer the status quo.

* Looking specifically at the TMR group two years after leaving school indicates a different pattern of parent

preferences. Half of the parents of youngsters who are not involved in any vocational programming two years post-school prefer "stay at home" or "other (nonvocational) activity" for their youngsters. The parents of youngsters in activity centers prefer: activity centers (44%), sheltered workshops (22%), and competitive employment (11%).

Parents' Preference for Youngsters' Living Arrangement

One-year follow-up:

* The parents of non-SPMR center completers whose youngsters live with them strongly (67%) prefer them to remain at home. 13% would like to see their youngster eventually living independently, 12% would prefer their youngster in a group setting.

* Parents of TMR youngsters express the preference for their youngsters living with them even more strongly. 80% of parents whose youngsters live with them prefer that arrangement, 18% prefer a group setting, and 2%, an independent living situation.

* Parents of mainstreamed youngsters show a different pattern of preferences. Only 38% whose youngsters live with them prefer that arrangement, an additional 38% would like to see them living independently, and 4% prefer a group setting of some kind for their youngsters.

Two-year follow-up:

* Judging by findings from the two-year follow-up cohort, parent preference for youngsters living with them appears no to diminish after two years. 66% of the parents of 1985-1986 non-SPMR school completers whose youngsters live with them prefer this arrangement. 9% prefer an independent living arrangement and 6%, a group situation, for their youngster.

* 86% of the parents of TMR youngsters who live with them after two years prefer this arrangement. 5% prefer a group setting.

Relationship of Present Situation to In-School Vocational Training

* The relationship of highest level of in-school vocational training to present vocational situation was explored for all study groups. A number of chi square analyses of this relationship approached, but did not reach, significance.

* Only two chi square analyses pertaining to this relationship

proved significant. It was found that center-based EMRs who had had coop and/or AVTS experience were more likely to be employed one-year post-school than those who were not involved in these activities. (The relationship of work status to each of these placements alone was not significant.)

* Also, for the second-year EMR center completers, the higher the level of vocational training, the higher the likelihood of being employed. By their second year out of school, 90% of the youngsters who had reached the highest AVTS level, 75% who had reached co-op level, and 43% of those who had reached the lowest level were employed.

* Since it is more able youngsters who reach higher levels of training, the contribution of greater ability, and of training to being employed cannot be individually determined. It is likely that a combination of both enhances vocational potential.

Matches Between Field of Employment and Previous Training

* The vocational training backgrounds of employed youngsters were examined to determine whether their field of work matched any of their past training experiences. Two such matches were found in last year's follow-up.

* 12 matches were found for the 1986-1987 cohort interviewed this year. 8 out of 13 employed EMR center completers, and 4 out of 17 employed mainstreamed completers, have jobs which match elements of their past training. A typical match is a restaurant worker who had a center course and coop experience in food service.

Relationship of Number of Parents to Employment Status

* The relationship of number of parents to employment status was found to be significant for 1987 EMR completers. Those who come from 2-parent families are more likely to be employed than those from one-parent families ($p<.05$). 84% of employed EMR completers come from two-parent families.

* This relationship could not be explained in the research. Variables that might be expected to vary for 1- and 2-parent families - SES, education of parents, total number of children, number of children living at home, and income - proved not to relate to employment status.

* A number of hypotheses were suggested to explain this finding. There were not testable with the present data, but may serve to suggest directions for further research.

* This finding does suggest, however, that one-parent families with handicapped children may warrant special attention.

CONCLUSIONS AND ISSUES

This section of the report discusses conclusions drawn from the findings of the studies, and issues that arise from these conclusions. Proposed action steps related to the issues are presented.

Conclusion I: An extremely high percent of youngsters live with their parents and guardians after completing school. In the one-year follow-up, it was found that half of this year's SPMR cohort, and over 80% of all other cohorts, live with their families. After two years, over 80% of both TMR and EMR youngsters remained with their parents. As we noted in last year's report, these percents are higher than that found in any similar follow-up study in the literature.

Parents' attitude towards this living arrangement indicate a strong preference for this arrangement. Even after two years, 2/3 of parents with non-SPMR completers living at home state that they want their youngsters with them in the future. Almost all parents of SPMR completers whose youngsters live with them state this preference, although there is evidence that some are beginning to realize their own limitations and to seek alternatives.

The situation of TMR youngsters appears to be more extreme than the group as a whole. The one year follow-up indicates 87% of TMR completers living with parents and guardians. After two years, 86% of parents of TMRs state this as their preference for the future.

Issue 1: The arrangement in which mentally retarded adults live indefinitely with their parents is not without cost to the mentally retarded adult, the parents, and other family members. Studies have indicated the problems and stresses that arise in a family when a mentally retarded person continues to live in the parental home. One recent study found the lives of mentally retarded adults living with their parents to be limited in a number of ways:

> First, their social lives were found to be extremely limited. Their companions were exclusively family members or other people with a mental handicap . . . . Secondly, while they had the opportunity to use some self-help skills at home, this was only at a very basic level. Finally, they were given only limited autonomy in very basic aspects of their lives, their parents exercising a large degree of control and protection. (Cattermole, et al, 1988)

Another study of such families found that "both the person and the parents led restricted lives, the person remaining highly

dependent upon the parents and having little or no life outside the home. But perceived deficiencies in residential services made parents unwilling to contemplate the idea of their son or daughter leaving home, often wanting him or her to live with them until the parents died or became unable to cope" (Wertheimer, 1981, cited in Cattermole, et al, 1988).

Issue 2: **The arrangement in which a mentally retarded adult remains in the family home cannot be maintained for the life of the adult child.** Mentally retarded adults are now enjoying normal lifespans. These living arrangements, then, break down eventually as parents age and die, creating a crisis situation as alternative arrangements are sought for the aging mentally retarded individual. Sometimes the burden shifts to a sibling, perpetuating the cycle of strain and dependency. It should be noted that in the present study, even when parents preferred their youngsters to remain with them they expressed their own, and their youngsters', concerns in this area: "I'm (or he's) concerned what will happen to me when I am no longer around." Keeping a youngster at home, may just postpone the problem of finding more independent living arrangements until the individual reaches an advanced age and has decreased ability to adjust to new circumstances. It has been suggested that there exists a "need to provide opportunities for people with a mental handicap to leave the family home at an age close to that of non-handicapped people" (Cattermole, et al, 1988).

Proposed Action Steps: This appears to need to be recognized and addressed as a problem. Right now, it is a "silent problem". The families accept this situation and pay the inherent emotional, financial and other price. Few demands are made on the service system. A number of steps could be taken:

* **Research on the situation.** What are the resources available for housing for the mentally retarded? Do parent preferences reflect a lack of adequate services, or parent disinclination to utilize services that actually exist? What are the current waiting lists for community living options? Are there services and alternatives that need to be developed or expanded? What are the barriers to current use? What are parents looking for in housing for their children? Do the options currently available meet parent standards? Are parents aware of the alternatives that do exist? If not, are there ways possible to disseminate this information more effectively?

* **Assistance for those families who express a preference for alternative housing arrangements.** Although a majority of the parents prefer their youngsters with them, one third of the parents of the non-SPMR group, and 42% of the parents of mainstreamed youngsters, prefer independent and group options. A number of parents of SPMR youngsters indicated interest in community living arrangements. These parents should be assisted in finding acceptable housing for their sons and daughters. Possibilities: An information and referral service, created to

coordinate and disseminate information on housing alternatives. If options in this area are found to be inadequate, development of more housing alternatives of different types.

* **Work with parents who prefer their children to remain with them to expose them to other options.** Parents would be introduced to other resources for their children's housing, and guided to an understanding of the drawbacks to the present arrangements, both in terms of present daily life and future inevitabilities. Parents could be linked to other similar parents who have youngsters living in more independent housing arrangements.

Conclusion II: A great deal still needs to be done to create satisfactory vocational outcomes for mentally retarded youngsters who have completed school. Vocational outcomes presently evident for youngsters post-school are not optimal. New supported work initiatives around the country have stressed that all such individuals, regardless of ability, should be assisted to become placed in competitive employment. There is little evidence in the present study that such initiatives have affected local school completers. Of the total group of EMR completers one year post-school, 1/3 are idle, 49% are working and 8% each are in activities centers and sheltered workshops. The statistics for TMR students indicate considerably poorer outcomes: one-year after school 40% are idle, 29% are in activities centers, 23% are in sheltered workshops and no one is working. Data for the second year, find that more EMRs are working (65%), and that TMR have shifted to activities centers (41%). About one in five youngsters in each cohort remained idle after two years.

Parent preferences for future vocational arrangement indicate that parents tend to prefer the activity in which their youngster is involved, or a higher level activity. A disturbing finding in this regard is from the second-year of the TMR in which parents appear to have given up the possibility of competitive work for their young adults. For those who are idle the second year, the parents largely prefer they remain at home or be involved in some other nonvocational activity.

Most of the parents whose youngsters are in activities centers and sheltered workshops appear to accept these as permanent placements for these young adults, sounding resigned rather than content with these arrangements: "I don't feel he has much of a future". "She is where she always will be." "No change is possible". Some are very bitter toward the system. They don't seem to know where to turn. Many have given up and resigned themselves to at best minimally satisfactory arrangements for their children.

This acceptance by parents of what professionals in the field would consider placements below youngsters' ultimate capabilities has been found in other studies. Findings from a recent study of young adults with MR are reminiscent:

> All of the parents whose young adults were in sheltered workshops indicated that this was a stable and terminal arrangement. Parents shared such comments as "won't go beyond that", "stay at workshop permanently", don't see any other possibilities" and "she will stay there". (Brotherson, et al, 1988)

Issue 1: Vocational options that parents are accepting for their children which do not involve competitive employment, are not congruent with state-of-the-art goals for retarded people in this country. These outcomes and parent attitudes towards them are puzzling to professionals in the field who are working with new approaches especially targeted to the more impaired. Supported employment initiatives assert that anyone can work given the proper long-term support. Parent outlook on the situation, however, is understandably based on the system with which they have dealt through the years and tends to involve goals for their children that prize safety, longevity and safeguarding of benefits above competitive employment opportunities.

Researchers puzzled by the finding that parents of moderately retarded persons tended to concur with the more severely involved group regarding working conditions for their children, program preferences, and attitude toward work concluded that:

> "It is probable that the attitudes of these parents have been influenced by the highly restrictive/protective services traditionally supplied to the person who are moderately retarded, particularly at the school-age level and also often at the adult service level in the form of the activity center or development center placement." (Hill et al, 1987)

These researchers suggest that parents and professionals may be applying different standards to acceptable outcomes, with parents concerned with assuring basic levels of safety and financial protection, and professionals concerned with real work outcomes:

> . . . parents and professionals involved with persons who are mentally retarded assess the adequacy of programs with different outcome measures. The typical outcomes of work which are important to program evaluators such as wages, consequential tasks, job advancement, and so forth, appear not to be important to parents with sons/daughters in mental retardation programs. Instead, perhaps due to disincentives for work in this county, protective outcomes measures, continued guarantees for financial aid, program longevity, and safety appear to be in use by parents. (Hill et al, 1987)

Researchers have confirmed the existence of a difference in

parent/professional perspective on the situation, with the parents seeing more limited goals for their children, especially the more impaired, and the professionals, caught up in new advances, stressing new opportunities. Professionals emersed in the field may erroneously assume that parents are operating with full awareness of the new changes in service options for the mentally retarded. Parents, instead are likely to assume that the system is largely the one with which they are familiar. Professionals need to understand this basis for parent concern.

> As new supportive/competitive employment options are initiated, parent needs for security and stability should be approached with sensitivity and respect because as "state-of-the-art" in service changes, parents may experience service "jet lag". (Brotherson et al, 1988)

Issue 2: Differing views by parents and professionals of appropriate goals for mentally youngsters have lead to misunderstanding, and bad feeling on both sides. They have also lead to fewer opportunities for young people as parents become disillusioned with the service system and skeptical of new approaches. Communication between the two sides may be poor. Parents may feel that professionals are insensitive to their needs and minimize their legitimate concerns for safety and security. One study found that:

> In the area of professional support, parents described numerous stresses and difficulties when working with professionals. There were examples of unhelpful professionals in various disciplines. Many parents felt that in planning for their son's or daughter's future, professionals were insensitive, offered little help, did not know about or offer alternatives, and did not speak "English". (Brotherson et al, 1988)

Parents are apt to be seen by professionals as uncooperative and overprotective, not willing to rise to the challenge of innovative approaches that will open up new lifestyles for their children.

In order to change this situation, new avenues to parent/professional interaction appear to be necessary. Are there ways in which agencies and parents can come together and renew their faith in one another in a way that will reopen the possibility of creating more satisfying lives for these young people and their families? Can disillusioned parents be re-connected with the systems and can the systems be sensitive enough to their concerns that they won't again be driven away? New sensitivity on both sides may be necessary.

A number of authors suggest the need for increased sensitivity of agency personnel toward parent concerns, and better communication between parents and professionals.

> . . . much more parent/professional communication is needed to improve parental expectations for the vocational potentials of their children who are mentally retarded. General results show that, at present, parents' expectations do not concur with the recently described professional expectations which hold that most persons who are mentally retarded can effect transition into the mainstream of employment . . . . survey data vividly illustrate the need for the development of a parent/professional partnership toward improved vocational services for persons with disabilities. (Hill et al, 1987)

Issue 3: Potential loss of benefits and disposable income act as disincentives to full-time competitive work. At present the system of benefits is such that it is not clear whether, and to what extent, youngsters are in danger of losing benefits with increased income. These benefits are considerable and may include SSI, Medicaid and food stamps. According to Conley the fact that "developmentally disabled persons receiving SSDI/CDB or SSI often find that acceptance of substantial work brings little financial gain and sometimes brings major financial loss, causes an obvious disincentive to work". He points out that:

> Disabled persons receiving what appears to be secure monthly income support and health care financing may be reluctant to accept jobs that are temporary or insecure and that pay little more than the value of their monthly benefits. (Conley, 1986)

Schloss, et al, 1987 analyzing balance sheets which they developed for three different income levels - no earned income, part-time income, and full-time income - found that, with the decrease in benefits associated with full-time work, net disposable income was roughly the same for individuals employed full time and those employed part-time. They assert that "there are no compelling incentives for full-time employment of handicapped persons". Knapp, 1988, in a rebuttal, states that this analysis is faulty given recent amendments to the Social Security Act, and that "net disposable income increases with full-time employment.". With the experts arguing this situation, is it any wonder that parents and disabled youngsters may choose to play it safe and not chance the possibility of reduced or eliminated benefits, and so shy away from full-time work opportunities?

Proposed Action Steps:

* **Training to expose parents to new vocational alternatives, deal with their concerns, and increase their willingness to get their children involved.** This may be the best way to increase youngsters' potential for competitive employment. Wehman et al (1988) suggest assuaging parent concerns by having them visit

technical centers and other training sites, and putting them in touch with parents of successful program graduates. Beckett and Fluke (1988) describe a training program that focuses on parents' reservations about supported employment. The course is aimed at educating parents about supported employment and providing a forum for addressing parent concerns. The parents are presented with a hypothetical case of a young man in a sheltered workshop who is suggested for supported employment in a paint store. Parents are asked to imagine they are his parents and to list the concerns they have in respect to this planned move.

The authors report that the lists of concerns that participants identify is long and almost overwhelming. Certain key concerns are mentioned: how will the other workers accept him, can he safely handle the job, what will happen to his benefits, how will he get to work, will he sit at home if it turns out he cannot do the job. These concerns are accepted and discussed as real and legitimate. Small groups are formed to address the concerns. Authors report that parents participate in the case study with intense interest and that by taking on the identity of the young man's parents, find it easier to express their own doubts and questions about their sons' and daughters' ability to make it in an real job. They work to analyze these concerns and develop a plan of action. Parents then consider and enumerate the potential advantages of supported employment. In stressing the effectiveness of such training in gaining the support of previously skeptical parents, the authors indicate that:

> Parents deserve and need both respect for their concerns and careful responses to their questions. Once they are given accurate information and support, parents are more able to have a vision of their child's work potential. They can then become committed to their children's future employment and can work with service providers to create a variety of employment opportunities. (Beckett and Fluke, 1988)

* **Increasing professional sensitivity to parent concerns and training professionals in effective communication skills.** It has been suggested in this respect that:

> There should be greater emphasis in all disciplines upon training professionals in effective communication skills with families as well as providing information on potential community alternatives for young adults with disabilities. (Brotherson, et al, 1988)

It appears that being involved in parent training as described above would also go far in increasing professionals' awareness of parent concerns, and accepting the legitimacy of those concerns. Beckett and Fluke (1988) found that, through participation in such training, "Professionals gain insight into the depth of parents' concern as well as the wealth of information that parents have to share".

* **Development of in-school supported work.** Supported work, combining on-the-job training with provision of long-term support seems an ideal program for in-school vocational training. Agencies stress that the younger the individual can be placed in a program, before he has time to regress in a period without work, the better his vocational potential. Parents in our study voiced their interest in on-the-job training. One of the principles of supported work has been an emphasis on the more severely handicapped. Such a program, thus, would provide new in-school vocational training options for the TMR youngsters, as well as exposing EMR youngsters to the world of work. Students could be introduced to jobs that may continue once school is completed. In-school supported work has been implemented at sites around the country and in Pennsylvania. The feasibility of implementing this approach in schools in this area should be studied.

* **Better resources for linking potential clients and programs.** Many of the parents we spoke with stressed their need for program information. As we saw in the study, there are parents, especially those with EMR youngsters, who are interested in competitive employment opportunities for their youngsters. We have also spoken to agencies who are having trouble recruiting individuals for job slots. There need to be ways developed to foster the interaction of potential clients and agencies. One possibility is a resource network to which agencies could send program information, and to which parents could turn for information. Optimally, a resource network would keep a list of potential clients, their interests and needs, and match them with program resources. Cohorts of school completers would sign up with the network before they left school, indicating their needs and interests, to which appropriate programs could respond.

* **The establishment of clear, unambiguous guidelines as to eligibility for SSDI/CDB, SSI, Medicaid and food stamps.** This would go far in freeing parents and youngsters to make rational choices as to the extent of their work involvement without worrying that they were thereby endangering important income and medical care resources. This is especially important in regard to Medicare as loss of medical eligibility is a major concern of parents and disabled adults. Few employed completers were found to be receiving medical or other benefits from their jobs.*

* Conley (1986) has a more ambitious suggestion in this regard. He argues that:

> Lifetime eligibility for SSDI/CDB, SSI, Medicare and Medicaid should be granted to persons who establish eligibility for these programs unless there is significant medical improvement. This will provide severely disabled persons with the security they may need to accept temporary, insecure and low paying jobs (and thereby reduce the public benefits they receive).

Conclusion III: Mentally retarded youngsters from one-parent families were less likely than those from two-parent families to be working one-year after completing school.

Issue 1: Mentally retarded youngsters and their families appear to be disadvantaged in comparison with their peers from two-parent families, and may need extra assistance to achieve vocational goals. Such families are apt to be in more difficult circumstances than both other single-parent families, and two-parent families with handicapped children.

Proposed Action Step:

* A specific emphasis on families with handicapped children should be included in initiatives to help single-parent families. Special programs directed toward meeting the special needs of single-parent families (e.g. Big Brother) should make efforts to include those with handicapped children.

STUDY SECTION I

FOLLOW-UP OF 1986-1987 SCHOOL COMPLETERS

FOLLOW-UP OF 1986-1987 SCHOOL COMPLETERS

This year we continued the work undertaken in 1987, in which 1985-1986 mentally retarded (MR) school completers of the Allegheny Intermediate Unit's (AIU) six special education center system were followed (Gordon, Goldbach and Katz, 1987). The AIU is the administrative unit responsible for education in all of Allegheny County outside of Pittsburgh and encompasses 42 school districts. This year's research included follow-up of the next years' cohort of completers. Parents/guardians of those youngsters with an MR involvement of any degree who completed their educations at a special education center in the 1986-1987 school year were contacted. This allowed us to double our sample of such completers, giving us a firmer basis for conclusions. In addition, another group was added to this year's study. We were able to develop a methodology to study mainstreamed completers of the same school year. These were youngsters with an MR disability who were in mainstreamed classes under AIU auspices in regular area high schools. These were all educable mentally retarded (EMR) youngsters, as in that year of completion, AIU mainstreamed classes for the mentally retarded had only been developed for EMR. (There are some younger groups of mainstreamed trainable mentally retarded (TMR) classes presently in the system.) In that they were mainstreamed, these youngster were considered, in the main, less handicapped and better able to be integrated than their peers in the special education centers.

The Study Subjects

Center completers: Center completers finished their educations at the six special education centers of Allegheny Intermediate Unit during the 1986 - 1987 school year. These centers, located around the county, serve the handicapped children of the school districts of suburban Allegheny County which are under the auspices of the Allegheny Intermediate Unit. Less disabled youngsters, and those judged able to handle integration with nondisabled peers, are mainstreamed into district schools. The centers, then, serve the more severely disabled, those with multiple handicaps, those with emotional problems as well as developmental delays, and those otherwise unable to be integrated into a mainstreamed setting. The study population was comprised of all students who left school in the identified year who had any degree of mental retardation (MR), whether as a primary or secondary disability. Students who graduated, received a certificate or left school without official termination were all included.

Mainstreamed students: Mainstreamed students completed their educations in an EMR class under the auspices of the AIU,

in one of 12 district high schools. These classes are physically located within a regular high school. These students typically have their own programming within the high school building, but may interact with non-handicapped peers in some non-academic classes, at lunch, extra-curricular activities, and in the normal flow in hallways. Students who graduated, or who left school without official termination at any time during the school year, were included.

Data Collection

As in last year's study, data collection involved two major tasks. First, was identifying appropriate students and recording information from school records. Second, was interviewing parents or guardians.

Identifying students and recording information from school records:

Center completers: To identify center completers, visits were made to each of the six special education centers, and the guidance counselors consulted. The counselors were able to identify those students who had completed their education in the 1986-1987 school year, and had an MR involvement. They also tended to know the students and were often able to provide additional insights into the youngsters' school careers and present situations.

The school record information sheet developed for last year's study was used to record information taken from each student's school folder. It included such information as primary and secondary disability; parents' name, address and telephone number; youngster's address and telephone number; vocational courses taken the center; involvement in co-op work placements; and attendance at an advanced vocational course at an Area Vocational-Technical School (AVTS).

Mainstreamed students: Identifying appropriate mainstreamed students, and obtaining school information on them proved to be a challenge, involving different approaches. We discussed possible alternatives with the AIU Exceptional Children's Program vocational coordinator. It transpired that the central AIU office maintained class rosters of those special education classes under its auspices in the school districts. These rosters contained names and addresses of students and parents, by high school. A methodology was developed by which the AIU class rosters were used to compile a list of probable 1986-1987 completers. This was done by comparing the lists for each high school class for 1986-1987, and for 1987-1988. Youngsters whose names appeared on the former list, but did not appear on the latter, were considered as probable completers. Also, many times a coded reason for leaving the class was given, which allowed

students who had moved or transferred to be disregarded. This proved to work well in determining students who had completed the system. It did sometimes later transpire that a student was still taking classes within the school system, for example remained at an AVTS; such students were discarded from the sample. It is possible that there were completers that were not found by this method. If they were missing from the 1986-1987 roster for some reason, we had no way of knowing of their existence.

Using class rosters to compile the study lists meant that we had no school career information. We used a number of approaches to obtain such information, especially vocational experience which we felt was extremely important. We sent the guidance counselors at each of the special education centers a list of the mainstreamed students we had identified from his area of the county, asking him to indicate those that attended vocational courses at his center. (Mainstreamed students have the option of coming to the special centers for half-day vocational courses.) Information sheets, which requested details on the student's vocational involvement at the center, were also sent. This was followed by telephone calls to the counselor, where necessary, to make sure that all such information was gathered. Also all co-op teachers at the special education centers, learning facilitators at the AVTSs (counselors in charge of special education students at these schools) and co-op teachers at the AVTSs were called. Each was read a list of the identified mainstreamed completers from his/her geographical area and asked to identify those who had participated in the specified vocational programming. These staff people were notably cooperative and knew their former students so well, that we were able to identify which youngsters had participated in which programs and for what time period. This was invaluable in furnishing us with information on the vocational background of these former students, which would have been otherwise unobtainable.

Interviewing parents and guardians:

The phone numbers taken from school records and roster lists were checked for accuracy using telephone directories and the Cole's Directory, which provides listings of all telephone numbers published in the telephone directory, arranged by number and by street address. Vigorous attempts were made to locate the parent, guardian or youngster. All leads were followed. For example, if the number listed yielded a relative who reported that the youngster no longer lived there but a sister might know where he was, attempts were made to locate the sister and so continue the trail to find the youngster. Also, numerous callbacks, at different times of the day, and different days of the week, were made to the identified numbers. In addition, interviews were scheduled at the interviewee's convenience. We began the interview by requesting permission and asking whether this was a convenient time to talk. If not, we called back at the time indicated, and if that time proved not convenient or the

interviewee was not there, we persevered until an interview was achieved. As in last year's study, if a youngster was in a group living situation or an institution, the tendency was to contact and interview an individual in charge of that situation rather than the parent. It was felt that such an individual would be more aware of the youngster's current living arrangement and activities.

The same questionnaire was used to interview all parents and guardians whether of center completers or mainstreamed students. The questionnaire was a very slightly modified version of that used in last year's study. It queried the interviewee as to the present situation of the youngster, demographic data on the family, work and training history since leaving school, and desires of parent and child vis-a-vis the youngster's eventual work and living situations.

The Study Sample

* The overall return rate of the study of 1987 completers was very high. The researchers were able to reach 87% of the center completers and 63% of those who had attended mainstreamed classes (see tables pages 24 and 25).

* 27 of the total 29 non-respondents were unable to be contacted because of problems such as telephone disconnection or wrong number. Only 2 were not be reached for other reasons (see table p. 26).

* Comparing center completers who were contacted and those who were not contacted, it can be seen that individuals in the very low wealth rating category, those who were Black, and those who had withdrawn from school had lower rates of inclusion in the study (see p. 24).

* Similar differences in response rates can be seen for mainstream completers. Although race was not known for this group, lower response rates are noted for those in the very low wealth rating category, and those who had withdrawn from school (see p. 25).

* The study sample, then, tends to be somewhat less representative of youngsters who have withdrawn from school, rather than received a diploma or certificate, and of those whose families are in the lower, rather than the higher wealth rating categories. Also, among the center completers, blacks are somewhat less well represented than whites.

COMPARISON OF RESPONDENTS AND NON-RESPONDENTS

Center Completers - 1987

	RESPONDED	DID NOT RESPOND	TOTAL	PERCENT RESPONDING
SCHOOL				
Mon Valley	7	5	12	(58)
Eastern Area	12	4	16	(75)
Sunrise	9	2	11	(82)
Middle Road	17	0	17	(100)
Western Hills	13	0	13	(100)
Pathfinder	14	0	14	(100)
WEALTH RATING				
Very High	15	0	15	(100)
High	12	1	13	(92)
Middle	8	0	8	(100)
Low	23	3	26	(88)
Very Low	5	6	11	(45)
Unknown	9	1	10	(90)
PRIMARY EXCEPTIONALITY				
EMR	34	10	44	(78)
TMR	25	1	26	(96)
SPMR	10	0	10	(100)
PH	1	0	1	(100)
SED	2	0	2	(100)
SEX				
Male	44	4	48	(92)
Female	28	7	35	(80)
RACE				
White	64	7	71	(90)
Black	8	4	12	(67)
COMPLETION STATUS				
Diploma	31	5	36	(86)
Certificate	37	2	39	(95)
Withdrawal	4	4	8	(50)
TOTAL	72	11	83	(87)

COMPARISON OF RESPONDENTS AND NON-RESPONDENTS

Mainstream Completers - 1987

	RESPONDED	DID NOT RESPOND	TOTAL	PERCENT RESPONDING
WEALTH RATING				
Very High	3	0	3	(100)
High	8	4	12	(67)
Middle	3	2	5	(60)
Low	6	4	10	(60)
Very Low	6	5	11	(55)
Unknown	4	3	7	(57)
SEX				
Male	16	8	24	(67)
Female	13	9	22	(59)
Unknown	1	1	2	(50)
COMPLETION STATUS				
Diploma	28	12	40	(70)
Withdrawal	2	6	8	(25)
AGE AT COMPLETION				
17	3	3	6	(50)
18	16	9	25	(64)
19	11	6	17	(65)
GRADE AT COMPLETION				
9	1	1	2	(50)
10	2	2	4	(50)
11	0	2	2	0
12	26	13	39	(67)
14	1	0	1	(100)
TOTAL	30	18	48	(63)

Response Summary - 1987 Cohort

RESPONSE SUMMARY	MAINSTREAM #	MAINSTREAM (%)	CENTER #	CENTER (%)	TOTAL #	TOTAL (%)
Completed interview	30	(63)	72	(87)	102	(78)
Unable to contact:						
Phone disconnected	7	(15)	3	(4)	10	(8)
Wrong number	9	(19)	6	(7)	15	(11)
No phone			2	(2)	2	(2)
Not reached	2	(4)			2	(2)
	48	(100)	83	(100)	131	(100)

Findings

The findings for the one-year follow-up are presented here by exceptionality group: SPMR, TMR and EMR. Where appropriate, findings will be presented together with those of last year's study, so that the most complete picture possible will be presented of mentally retarded youngsters' situations one year post-school. This means that for the SPMR and TMR groups, results for the 1985-1986 and the 1986-1987 cohorts will be reported. For the EMR group, three groups of one-year results will be presented: those for the 1985-86 cohort, the 1986-1987 center cohort, and the 1986-1987 mainstreamed cohort.

The SPMR Group

SPMR (Severely/Profoundly Mentally Retarded) is the most severely disabled category of mental retardation. Many youngsters in this category are nonverbal. A large percent have lived in institutions since they were very young, attending the special education center nearest their institution while they were of school age. Upon reaching 21, youngsters in these institutions receive a certificate of completion from school and then participate in adult activities within the institution. Some of those with severe physical problems live in hospital or nursing home settings. These youngsters do not generally participate in vocational training activities while in school. Findings for this group, then, focus on living situation and whether or not they are attending any type of activity center, either within their residential institution or from their home.

	1987 Completers		1986 Completers		Total	
LIVING ARRANGEMENT	#	(%)	#	(%)	#	(%)
With parent/guardian	5	(50)	3	(19)	8	(31)
Group Setting			5	(31)	5	(19)
Institution	5	(50)	8	(50)	13	(50)
	10	(100)	16	(100)	26	(100)

* A surprisingly high percent, half, of the SPMRs of the 1986-1987 cohort were found to reside with a parent or guardian, the other half are in institutions.

* Of this cohort, two of the institutionalized SPMRs and two of those living with a parent or guardian attend Therapeutic Activities Centers.

The TMR Group

Living Arrangement

* 21 of the 25 Trainable Mentally Retarded (TMR) youngsters (84%) who completed school in the 1986-1987 school year are living with a parent or guardian. Of the remaining four, 2 are in community living arrangements and 2 are in institutions. This can be seen to be quite consistent with last year's results.

LIVING ARRANGEMENT	1987 Completers #	1987 Completers (%)	1986 Completers #	1986 Completers (%)	Total #	Total (%)
With parent/guardian	21	(84)	24	(89)	45	(87)
Institution	2	(8)	2	(7)	4	(8)
Group Setting	2	(8)	1	(4)	3	(6)
	25	(100)	27	(100)	52	(100)

Present Vocational Situation

PRESENT SITUATION	1987 Completers #	1987 Completers (%)	1986 Completers #	1986 Completers (%)	Total #	Total (%)
Regular Job	-		3	(11)	3	(6)
Sheltered Workshop	5	(20)	7	(26)	12	(23)
Activities Center	7	(28)	8	(30)	15	(29)
Volunteer	-		1	(4)	1	(2)
No activity	13	(52)	8	(30)	21	(40)
	25	(100)	27	(100)	52	(100)

* The 1987 TMR completers in sheltered workshops participate for 25-30 hours per week (average: 29.4). Activity center participants attend for 20 to 30 hours per week (average 25.3).

* Activity center participants are brought to their sites either by van or by family car. Workshop participants walk, use public transportation or are transported by program-based transportation.

Vocational Background

* All of the 1986-1987 TMR completers were in Work Activity Centers (WACs) while in school. 18 (72%) had taken 3 or more years of WAC. For 14 (56%), WAC was their only vocational experience while in school.

* 9 TMRs took at least one vocational course at their special education center, as follows:

Course	#	%
Food Service	5	(55)
Auto Mechanics	2	(22)
Building/Grounds Maintenance	2	(22)
Cooking	1	(11)
Horticulture	1	(11)

(N=9)

* Two TMRs had co-op experience while in school: one as a laundry worker in a motel and the other as a food service worker at St. Peter's Child Development Center.

The EMR Group

Living Arrangements

* An overwhelming majority of the 1986-1987 EMR completers live with a parent or guardian one year after school: 84% of the total group, which breaks down to 80% of the mainstreamed completers and 88% of the center completers. This compares very closely with the 89% of last year's study cohort of center completers living with parents or guardians. 6 of this year's mainstream subjects (20%) and 3 (10%) of the center completers are living independently, either alone, with a spouse, or with a roommate. One center completer is in an institution.

* 5 of this year's mainstream subjects have children; of these, 3 are unmarried and living with a parent or guardian. None of the center completers have children; one is married and living with a spouse.

WORK AND LIVING ARRANGEMENTS ONE YEAR AFTER COMPLETION

Mainstream and Center EMRs

	MAINSTREAM		CENTER '87		CENTER '86		TOTAL	
LIVING ARRANGEMENT	#	(%)	#	(%)	#	(%)	#	(%)
With parent/guardian	24	(80)	30	(88)	25	(89)	79	(86)
Institution			1	(3)			1	(1)
Alone	1	(3)					1	(1)
With spouse	1	(3)	1	(3)			2	(2)
With spouse, children	2	(7)					2	(2)
With roommate	2	(7)	2	(6)	1	(4)	5	(5)
Other					1	(4)	1	(1)
Unknown					1	(4)	1	(1)
	30	(100)	34	(100)	28	(100)	92	(100)

	MAINSTREAM		CENTER '87		CENTER '86		TOTAL	
PRESENT SITUATION	#	(%)	#	(%)	#	(%)	#	(%)
Regular Job	17	(57)	13	(38)	12	(43)	42	(46)
Supported Work			3	(9)			3	(3)
Sheltered Workshop			3	(9)	2	(7)	5	(5)
Activities Center			1	(3)	2	(7)	3	(3)
Training	5	(17)			2	(7)	7	(8)
No activity	8	(27)	13	(38)	10	(36)	31	(34)
Unknown			1	(3)			1	(1)
	30	(100)	34	(100)	28	(100)	92	(100)

Present Situation

* Over half of all the EMR youngsters (52%) who completed school in 1986-1987 are engaged in competitive employment or supported work; 57% of the mainstreamed completers and 38% of the center completers. 3 of the 16 employed center EMRs are in supported work situations. (See table previous page.)

* One-third of all EMR completers are not involved in work or training activity of any kind; 27% of mainstreamed completers and 38% of center completers have no activity. 5 individuals who had been mainstreamed (17%) are in post-school training. 4 from the centers (12%) are in sheltered workshops or activity centers.

* It should be noted that the respondent's definition of the youngster's work situation was accepted by the researchers. It is difficult to ascertain the permanence and comprehensiveness of some situations that were thereby classified as competitive work; e.g. washing cars in the neighborhood, helping a neighbor install a kitchen. Some of these positions are clearly marginal, involving the youngster in work on a sporadic, rather than a regular basis.

* Looking at what is known then about the all the EMR individuals that have been contacted one-year after school completion, it appears that about a third (34%) are engaged in no work-related activity, almost half (49%) are in regular or supported work, and 8% each are in activities centers or workshops, and in training.

Types of Jobs

* As was found last year, restaurant/food service institutions are the most frequent work settings for employed EMRs. Of 33 EMR youngsters from the 1986-1987 cohort who are working (17 from mainstreamed settings and 16 from centers), 14 (42%) are employed in restaurants, fast food outlets or sandwich shops. This is the same percent found for last year's cohort of employed completers. (See table next page.)

* The remaining workers from this year's cohort are employed in a variety of jobs. Center completers are working as janitors and laborers, and one each is working as a meat cutter and a nurses aide. The remaining mainstreamed youngsters are employed in a more diverse range of jobs which includes car jockey, electrical apprentice, stock clerk and social service aide.

WORK SITUATIONS ONE YEAR AFTER COMPLETION
Mainstream and Center EMRs

	MAINSTREAM		CENTER '87		CENTER '86		TOTAL	
TYPES OF JOBS	#	(%)	#	(%)	#	(%)	#	(%)
Restaurant/food service:	7	(41)	7	(44)	5	(42)	19	(42)
Dishwasher/Cook	1	(6)					1	(2)
Dishwasher			2	(13)	1	(8)	3	(7)
Busboy	1	(6)					1	(2)
Busboy/Dishwasher			1	(6)	1	(8)	2	(4)
Counter Helper	2	(12)					2	(4)
Pizza Cook/Delivery					1	(8)	1	(2)
Misc. Restaurant	3	(18)	4	(25)	2	(17)	9	(20)
Other:								
Armed Services					1	(8)	1	(2)
Assembly	1	(6)					1	(2)
Car Jockey	1	(6)					1	(2)
Courier	1	(6)					1	(2)
Electrical Apprentice	1	(6)					1	(2)
Gas Station Attendant					1	(8)	1	(2)
Janitor			3	(19)	3	(25)	6	(13)
Laborer	1	(6)	2	(13)			3	(7)
Meatcutter			1	(6)			1	(2)
Mechanic					1	(8)	1	(2)
Nurse Aide			1	(6)			1	(2)
Painter	1	(6)					1	(2)
Sales Clerk	1	(6)					1	(2)
Social Service Aide	1	(6)					1	(2)
Stock Clerk	1	(6)			1	(8)	2	(4)
Usher	1	(6)					1	(2)
Unknown			2	(13)			2	(4)
	17	(100)	16	(100)	12	(100)	45	(100)

Characteristics of Job Situations

* 10 (58%) of the mainstream workers from the 1986-1987 cohort found their jobs through friends or family members (5) or by applying on their own (5). In contrast, center completers who work tend (11 out of 16 or 69%) to have been referred by one of the six special education centers or by a placement agency (OVR, VRC, CEO, Parc-Way Industries).

* 15 of the 17 mainstream workers (88%) get themselves to work, either by car, bus or walking. Half of the center youngsters are also self-reliant, with another third being driven to work by a friend or family member.

* Most (59%) of the mainstream workers have held their current jobs for less than a year; 8 (47%) had obtained their present jobs in 1988. In contrast, 9 of the center youngsters working (56%) are in jobs they had acquired at least a year ago; 3 of the 16 (19%) have been at their present jobs for 3 years or longer.

* 53% of workers from the mainstream group, and 62% of those from the centers (55% of all EMR workers), are working less than full-time. The remaining workers - 47% of mainstream workers and 38% of center workers - work at least 35 hours a week.

* All but two of the workers are earning more than minimum wage. 9 of the 33 workers (27%) are earning $3.35/hour; 12 (36%) are earning $3.50 or over. The highest wage earner receives $6.00/hour. Mainstream workers earn slightly higher wages, on average, than the center workers ($3.82 vs. $3.54). Rate of pay was not known for 10 (32%) of the workers.

Vocational Background

* Half of the mainstreamed MRs and nearly three-fourths (74%) of those from centers had taken at least one vocational course at a special education center. Food Service and Building/Grounds Maintenance were popular, particularly among the center EMRs. However, a variety of courses were taken by both groups: the 15 mainstreamers took courses in 8 different areas; the 25 center EMRs worked in 10 subject areas. 13 center EMRs participated in WACs at their schools. (See table next page.)

	MAINSTREAM		CENTER		TOTAL	
CENTER VOCATIONAL COURSES	#	(%)	#	(%)	#	(%)
WAC	0	(0)	13	(38)	13	(20)
Food Service	5	(17)	13	(38)	18	(28)
Building/Grounds			10	(29)	10	(16)
Clerical	3	(10)	2	(6)	5	(8)
Auto Body	3	(10)	1	(3)	4	(6)
Auto Mechanics	2	(7)	2	(6)	4	(6)
Materials/Warehousing			3	(9)	3	(5)
Carpentry	1	(3)	1	(3)	2	(3)
Construction	2	(7)			2	(3)
Marketing/Dist. Ed.	1	(3)			1	(2)
Graphic Arts	1	(3)			1	(2)
Cooking			1	(3)	1	(2)
Waiter/Waitress			1	(3)	1	(2)
Diversified Occupations			1	(3)	1	(2)
None	15	(50)	9	(26)	24	(38)
	N = 30		N = 34		N = 64	

* 47% (14 individuals) of the mainstream completers took courses at an Area Vocational-Technical School (AVTS), as did 7 center completers (21%). The 14 mainstreamed AVTS students took courses in 10 different subject areas, ranging from appliance repair to cosmetology. The students from the centers tended to be concentrated in a few AVTS areas, with this cohort, for some reason, concentrated (4 out of the 7) in meatcutting.

	MAINSTREAM		CENTER		TOTAL	
AVTS COURSES	#	(%)	#	(%)	#	(%)
Meatcutting			4	(12)	4	(6)
Health Ass't/Occupations	1	(3)	1	(3)	2	(3)
Appliance Repair	2	(7)			2	(3)
Auto Body	2	(7)			2	(3)
Electronics	2	(7)			2	(3)
Marketing/Dist. Ed.	2	(7)			2	(3)
Materials/Warehousing	2	(7)			2	(3)
Auto Mechanics	1	(3)			1	(2)
Baking	1	(3)			1	(2)
Construction	1	(3)			1	(2)
Cosmetology	1	(3)			1	(2)
Cooking			1	(3)	1	(2)
Diversified Occupations			1	(3)	1	(2)
None	16	(53)	27	(79)	43	(67)
	N = 30		N = 34		N = 64	

* 20 of the 34 center EMRs (59%) participated in co-operative education in 9 different types of work settings. Only 7 (23%) of the mainstream youngsters were involved in co-op. For both EMR groups, the most frequent co-op setting was a restaurant, where 15 (23%) of the students had job placements.

	MAINSTREAM		CENTER		TOTAL	
CO-OP PLACEMENT SITES	#	(%)	#	(%)	#	(%)
Restaurant	5	(17)	10	(29)	15	(23)
College/School			4	(12)	4	(6)
Health/Social Service			3	(9)	3	(5)
Supermarket	1	(3)	1	(3)	2	(3)
Warehouse			2	(6)	2	(3)
Municipal Government			2	(6)	2	(3)
Dept./Retail Store	1	(3)			1	(2)
Motel			1	(3)	1	(2)
School District			1	(3)	1	(2)
Unknown			1	(3)	1	(2)
None	23	(77)	14	(41)	37	(58)
	N = 30		N = 34		N = 64	

* In sum, in-school vocational involvement differed for the two groups of EMR students. The center-based students were particularly involved in courses in their own schools (74%), and in co-op placements (59%). Some (38%) participated in WACs in their centers, and a smaller percent (21%) went to the AVTSs for courses. The mainstreamed students' vocational experience tended to include courses at the special centers (50%) and at the AVTSs (47%), with less than a quarter (23%) of the students participating in co-op. Mainstreamed students were more likely than center-based students to have had no in-school vocational involvement (23% versus 6%).

	MAINSTREAM		CENTER		TOTAL	
VOCATIONAL EXPERIENCES	#	(%)	#	(%)	#	(%)
WAC	0	(0)	13	(38)	13	(20)
Center Vocational Courses	15	(50)	25	(74)	40	(63)
AVTS Courses	14	(47)	7	(21)	21	(47)
Coop Placement	7	(23)	20	(59)	27	(42)
None	7	(23)	2	(6)	9	(14)
	N = 30		N = 34		N = 64	

* A number of EMR completers have had additional vocational training since leaving school. 30% (9 individuals) of mainstreamed completers have taken courses in fields such as food service, clerical work and photography. 4 center completers (12%) have had post-school courses, primarily in the janitorial field.

	MAINSTREAM		CENTER		TOTAL	
POST-SCHOOL TRAINING	#	(%)	#	(%)	#	(%)
Food Service	3	(33)			3	(23)
Janitorial			3	(75)	3	(23)
Clerical	2	(22)			2	(15)
Photography	1	(11)			1	(8)
Cook	1	(11)			1	(8)
GED	1	(11)			1	(8)
Other	1	(11)	1	(25)	2	(15)
TOTAL	9	(100)	4	(100)	13	(100)

STUDY SECTION II

TWO-YEAR FOLLOW-UP OF 1985-1986 SCHOOL COMPLETERS

TWO YEAR FOLLOW-UP OF 1985-1986 SCHOOL COMPLETERS

The second major aspect of the 1988 Trees study involved re-contacting the parents/guardians of the youngsters who had completed school in the 1985-86 school year. These individuals had been interviewed last year as to the status of their youngsters one year after leaving school. This year's study informed us of these youngsters' situation two years after leaving school.

The methodology of the study was the same as the one-year follow-up. Parents/guardians, or living arrangement supervisors were interviewed by telephone. The questionnaire was modified somewhat. So as not to unduly tax the respondent, information on family characteristics which had already been collected was not asked again. The focus was on present living arrangement and work situation, as well as jobs and training undertaken in the year since last contact. As in the one-year questionnaire, parents/guardian were asked their own and their youngster's preferences for employment situation and future living arrangement. Those parents whose youngsters were not working or in training at the time of interview, were again asked why they felt he/she wasn't working.

An item was added to the two-year questionnaire which queried whether the parent felt more encouraged, about the same or more discouraged regarding their youngster's future than they had since he/she was in school, and asked the reasons for this. As will be seen, this often elicited a great deal of feeling and cogent comment.

The interviewers were able to reach almost all of the study population. Only 4 individuals could not be contacted: 1 had moved with no forwarding address, 2 had disconnected phones, and for 1, telephone contact could not be made within the required time period. The exceptionalities of the four who were not included this year were: EMR, EMR/LAP and two TMR's. In addition, there were five youngsters who reside in an institution about whom information was obtained this year and not obtained last year. The exceptionality of these five individuals were: 4 SPMR and a TMR. Total sample size therefore, remained quite constant; 80 in 1987, 81 in 1988.

The discussion below, then will focus on the three MR groups which comprise the main body of the 1985-1986 cohort: SPMR, TMR and EMR. As in last year's study, the numbers of PH (physically handicapped and SED/LAP (Socially and Emotionally Disturbed/ Learning and Adjustment Problem) were two small to permit conclusions and will not have a separate discussion. The youngsters' living arrangements and vocational situations two

years after leaving school will be discussed. Also covered will be parents' feelings about their youngsters' future. A unique element of this section will be the presentation of parents' comments in some length. We felt that we had really begun to know these youngsters and their parents or guardians, after following their school careers and speaking to them one and two years post-school. These parents had a lot to say about their lives with their handicapped sons and daughters and were so expressive about saying it. We decided that presenting their feelings, in their own words, would allow the reader to become acquainted with them in a very immediate way. For these reasons, SED/LAP parent comments were also included. Additional findings from the two-year follow-up, including reasons given for lack of work activity, and parent preferences for youngsters' future vocational and residential situations, will be included in the following section which specifically focuses on these variables.

The SPMR Group

Activities and Living Arrangements

The table below indicates the activities and living arrangements of the SPMR subjects who have been out of school for two years. 3 individuals live at home, 3 in group settings and the remainder, 13, in institutions. All but 3 of the institutionalized youngsters participate in activity centers of some kind.

ACTIVITIES AND LIVING ARRANGEMENTS OF SPMRs
1986 Cohort - Second Year

	Parent or Guardian	Group Setting	Institution	Total
Attending Activities Center	3	3	10	16
Not Attending Activities Center	-	-	3	3
TOTALS	3	3	13	19

In order to acquaint the reader more vividly with the SPMR group, each SPMR youngster living with a parent or guardian will be briefly presented. These include 5 from the 1986-1987 cohort and 3 individuals from the 1985-1986 cohort. These summaries are taken from interviews with parents/guardians. Descriptions of general situation as well as parent preference for youngster's living arrangement in 3-5 years will be discussed. Also included for the 1986 cohort will be responses to the question regarding

parents' feelings about their youngsters' futures.

1987 cohort

Youngster lives with legal guardian, is blind and deaf, cannot walk or talk. Guardian's preference for youngster's living arrangement in 3-5 years: live with guardian.

Youngster attends a TAC 2 days/week. A therapist comes to the home for a 2 days/week for a few hours each day. Youngster is not verbal. Parent's preference for future living arrangement: live with parent.

Youngster is on a waiting list for a TAC. Illness prevented enrollment when youngster's name came up previously. Parent's preference for future living arrangement: live with parent.

Youngster is in a WAC run by United Cerebral Palsy for 27 1/2 hours a week, 5 days a week. Parent's preference for future living arrangement: live with parents.
These parents elaborated further on their situation: The family was motivated to move to Washington, PA because youngster could attend an activities center there five days a week while the best they could obtain in Allegheny County was a center with a year's wait for a program offering 3 day/week attendance. The father and mother feel a need for respite care so that they could get away for a weekend or week. They feel bitter that they who do not seek full-time residential care for their son receive little in the way of supportive services from any public agencies.

Youngster has a mentality of a 6 month old child. He is on the waiting list for Allegheny Valley School, a residential institution. Parent's preference for future living arrangement: residential institution.

1986 cohort

Youngster has attended a WAC from Monday to Friday for the past two years. "He loves it; hates changes in routine."
Parent's preference for future living arrangement:
1986 response - live with parents.
1987 response - depends upon the health of the parents. It takes two to manage him. Would prefer him to: 1) live with parent. 2) Live in CLA or group setting.
Feelings about future: "We feel about the same regarding his future. We have tried to be realistic. There is no concrete reason to feel encouraged. He needs to find the closest thing to home in the future."

Youngster attends TAC for 30/week. He has no speech.
Parent's preference for future living arrangement:
1986 response - CLA or group setting.

1987 response - 1) Live in CLA or group setting.
2) live with parent.

Feelings about future: "Content at the moment, worried about future. We hope for a group home. We would prefer him to be with a relative but that can't work. Youngster will need group setting."

Youngster has been at a TAC for 25-39 hours/week at both year's interview. Child gets bored and irritable at home. Needs to be active. Mother needs a break.

Parent 's preference for future living arrangement:
1986 response - live with parents "as long as health maintains".
1987 response - live with parents.

Feelings about future: "Child is profoundly retarded but has made meager progress. He enjoys being at the center. He needs constant supervision."

It is clear that these parents are living with a heavy burden in caring for a very retarded individual. However, all but one of these families would prefer their youngster to remain with them in the future. Perhaps this tends to changes over time, as 2 of the 3 with youngsters who have been out of school for 2 years are considering alternative living arrangements. Questions remain as to what these parent preferences reflect in the light of the difficulties that such care represents: Is there a paucity of acceptable residential facilities? Are parents aware of the alternatives that do exist? Will these families be able to care for their youngsters indefinitely? What are the long-term effects on these parents of such care? Are there ways to facilitate parents' use of support services and exploration of alternative living arrangements?

The TMR Group

Living Arrangement

* 22 out of 27 (81%) were living with their parents both years. In 1988, there was one youngster living alone, 2 in group settings and 2 in an institution.

Vocational Situation

	1987		1988	
	Num.	%	Num.	%
Idle	7	26	6	22
Activities Center	9	33	11	41
Sheltered Workshop	7	26	6	22
Job	3	11	2	7
Volunteer	1	4	2	7
Total	27	100	27	99

* Activities center, which includes Therapeutic Activity Center (TAC), a nonvocational setting, as well as Work Activities Center (WAC), remains the most frequent placement both years.

* There were 4 youngsters whose situation changed between the two years: one was idle in '87 and is now in an activity center, the second was idle in '87 and is now a volunteer, a third was previously in a workshop and is now in an activities center, and the fourth was working last year and is now idle.

Parents' Feelings About the Future

Encouraged	7 (26%)
Same	
Positive	1 (4%)
Negative	8 (30%)
Discouraged	4 (15%)
No answer	7 (26%)
	27 (100%)

* Grouping these into generally positive and generally negative parental attitudes towards youngsters' futures: 8 or 30% feel more encouraged about their youngster's future or have about the same positive view as they had had while he/she was in school; 12 or 45% feel more discouraged or have about the same negative view they had had while the youngster was in school.

* There was no relationship between feelings about the future and present vocational situation.

TMR Parent Comments

Parents' explanations of their feelings about their youngsters' futures are often very insightful, especially as they relate to the youngsters' situation.

Youngster in TAC Both Years

Parents whose TMR youngster was in a TAC at both years' interview express a variety of feelings regarding this situation. Some declare themselves more encouraged regarding their youngsters' future, some as about the same, and some as more discouraged. Some of the comments made by parents:

More encouraged

"She has shown improvement in maturity and ability to work. I think she's learning at center, think she could mature more. She does more than she used to around the house because I (stepmother) encourage her participation."

"TAC encourages him to do more. He loves the TAC."

About the same

"Haven't seen any improvement. Child earns no real money. It actually costs me to send him."

"I know her limitations and where she will be. No change is possible. Before she got into the TAC, she sat at home treading water."

(Youngster in TAC 2 days/wk)
" North Hills area is very lacking in options for people in this situation. Would like to see sheltered workshop in a closer area than Sharpsburg. Would like to see more suburban facilities. Some young adults have nothing to do. She was frustrated and irritable sitting at home. Needs interaction with others."

More discouraged

"I don't feel he has much of a future."

"He was happier at school and fit in better. Center is a mixture including people with mental problems. People at school were peers. He has a large combination of problems including his frustration and jealousy watching normal siblings doing normal things."

Youngster in Sheltered Workshop Both Years

Parents of TMR youngsters who were in a sheltered workshop at both years' interview similarly express a variety of feelings regarding that situation. Some feel more encouraged about their youngsters' future, some about the same, and some more discouraged. As parents commented:

More encouraged

"She has a good future. She can take some care of herself. She could not live on her own but I don't have to do much for her. She is at about a nine year old level."

"He has very poor eyesight. He is doing well - has a good attitude, and that means a lot to us. He looks forward to going to work every day and is doing well at what he does.

Happy at work and happy at home. Everything is okay."

"He is very comfortable with the situation and that makes me happy."

About the same

"There isn't anything out there but waiting lists. I have had to fight for everything I have gotten for him."

More discouraged

"She is where she will always be."

"I am very bitter about the lack of information coming from the schools about what the future holds - long waiting lists for workshops, for example. I am also bitter about the lack of ongoing education. She cannot read or do math, and has come to realize that she wants to read. There is nothing available to facilitate this."

Youngster Idle Both Years

The parents of youngsters who have not worked since leaving school describe themselves as feeling about the same, or more discouraged about the future. Some examples:

About the same

"I'm optimistic. I feel that God gave me this child for a reason and that he takes care of his own."

"Didn't accomplish anything. Mon Valley teacher was excellent, but he was transferred to other teachers who handled him badly and I took him out of school. He has a bad heart. I am dissatisfied because there is not enough individualization and schools think they know better than the parent what the child needs."

"When . . .son was ready to graduate, (AIU) sent a letter home stating that if parents wanted to know about further possibilities for their children, they should contact the AIU. Too little, too late. Youngsters need ongoing stimulation with peers. Parents must take the initiative to see that the right thing is done. There is not enough individualization, not enough future programs."

More discouraged

"He liked school. He would like education and I would like to see him go. I don't know or think there is a program for him. My major concern is for the future when I'm gone, although I have confidence in my daughter, who is designated

guardian."

Youngster Employed Both Years

One of the two parents of TMR youngsters who were employed at both year's interviews described herself as feeling about the same regarding his future, the other as more encouraged:

About the same

(Youngster works in maintenance at motel since 9/83, 30hrs/wk; $3.35 +/hr.)
"He's kind of shaky, Capable at times but immature. He likes to work and would work full time but insurance would not cover his needs. He would like to marry and leave home. His potential spouse is also on SSI."

More encouraged

(Youngster works in Father's business since 1984 and in variety store/restaurant across the street since 1/86. In 1988: 16-20 hrs/wk; $15/wk.)
"He has had a lot of positive public exposure - has 4 siblings. He has been a joy. I am completely satisfied with system. Some parents expect too much from the system and kids. The work is important to him. He takes real pride in the work. He's doing the best he can with what he has. I fear Altzheimer's for him; it's hereditary in family and falls in the same chromosome as Down's. That's my current worry."

The EMR Group

Living arrangement

* Of the 26 EMR youngsters, 21 (81%) live with parents or guardians two years after leaving school. Two individuals live with spouses, one with children, one with a roommate, and one is in the Navy.

* The only change in the living arrangements of this cohort from the first year out of school to the second is that two youngsters who lived with parents/guardians last year now live with spouses.

Vocational Situation

	1987		1988	
	Num.	%	Num.	%
Idle	9	35	6	23
Activities Center	2	8	2	8
Sheltered Workshop	1	4	1	4
Training	2	8		
Job	12	46	17	65
Total	26	101	26	100

* The situation shifted to a higher percent of the group with a job and fewer idle than last year. Because the numbers are small, it should be stressed that 7 individuals' vocational situations changed between 1987 and 1988: 4 who were idle in 1987 are now employed; 2 who were in training are now employed; and 1 who was employed is now idle.

Parents' Feelings About the Future

Encouraged	10 (38%)
Same	
Positive	1 (4%)
Negative	2 (8%)
Discouraged	11 (42%)
No answer	2 (8%)
	26 (100%)

* Grouping these into generally positive and generally negative parental views of youngsters' futures: 11 or 42% feel more encouraged about their youngster's future, or have about the same positive view as they had had while he/she was in school; 13 or 50% feel more discouraged or have about the same negative view they had had while the youngster was in school.

* There was no relationship between feelings about the future and present vocational situation.

EMR Parent Comments

Youngster Not Working Both Years

The parents of youngsters who have not been working since they left school describe themselves as more discouraged about

their youngsters' future. As they explain their feelings:

"He's not job ready. He's been out of school for so long. Inactivity leads to lower skills and motivation."

"Nothing is happening. Its a stagnant situation. I'm disappointed in the system because I was not informed before my daughter left school as to what her future would be. She talks about work all the time."

"Society and job situation will make it difficult for him to be self-supporting and have benefits. A job would rapidly advance his maturity".

A number of these parents feel additional training or assessment of the youngster is needed but have been unable to arrange this:

"His counselor at Allegheny East recommends training, but there are no avenues for getting cost paid for. I feel he needs training for a good paying job".

"School said she should be tested; we can't get her covered under our medical insurance and so can't afford to have testing done. She's not high functioning enough to work in a regular job, and can't get into a training program unless she has the assessment done". (This comment was originally made in 1987, and repeated in 1988 interview.)

Youngster Working or In Training Both Years

As might be expected, a number of the parents whose youngsters were working or in training at both year's interviews described themselves as more encouraged about their youngster's future:

"She is more capable of holding a job and is open with people; more independent."

"I see a big change since working. She's trying for good social interaction and independence."

(Youngster presently in a training program at CCAC.) "School is pampering. She's learning more about the world and can handle it."

There are however, probably an equal number of parents of such youngsters who feel about the same (with a negative comment), or more discouraged, for various reasons:

(Youngster who works at McDonald's for 20 hours/wk in a job she began as a coop student and recently completed vocational evaluation.)
"I tried to get something better for her but nothing happened. The agency where she had some vocational evaluation and kitchen work was not very communicative about what she did there or her capabilities. They called me about a month ago about a job, but I have heard nothing since."

(Youngster in supported employment both years, in the stockroom of a department store last year, as a busboy/diswasher in a restaurant this year: 21 hrs/wk, $3.75/hr. Between these jobs, he had been a janitor in a bakery. He left this job because, as his father describes it, "He had been trained in food service and at the bakery he was a flunky.")
"I am more discouraged. His experience at Middle Road was fine. He was later tested and declared of normal intelligence. He was put in a training program away for home and, after 4 months of trying to cope, attempted suicide. He was hospitalized and is still under psychiatric care. I worked hard to find a placement for him and was very frustrated. I feel his emotional problems were caused by being messed around by the system. I hope to help him achieve independence."

"She'll be okay but needs a lot of help."

"He can do better and will do better when he gets it together."

Youngster Not Working Last Year, Working This Year

A number of parents whose youngster was not working last year, but is working this year feel more encouraged because of this change in situation:

(Youngster who had had training in autobody and was described last year as "having his heart set on doing autobody work" and not being able to find a situation. He is now working as a supermarket bagger for 25-30 hrs/wk):
"His socialization is very good. He's not the same as he was 2 years ago. His self-esteem has improved. He's very interested in the store."

(Youngster in CCAC janitorial service program and working as a janitor.)
"I am more encouraged. He wants to go to school and work."

One mother whose youngster is now working appears quite bitter towards the system:

(Youngster is doing kitchen work at a restaurant 16 hrs/wk.) "He did not have training for job function. He was high functioning and did not receive proper attention. He needed on-the-job training. School wants people to go to other agencies to find a place after schooling is over. He could have had a lot more going for him if he had had the right training. I found his present job for him totally by accident when I was at my wits' end about what would be next for him."

Youngsters in Activity Centers or Sheltered Workshops Both Years

A number of youngsters have been in activity centers and sheltered workshops for both years and some parents are satisfied. This seems to depend upon parental expectations:

(Therapeutic Activity Center (TAC) both years. This would be considered a low level placement for a youngster judged EMR.)
"I feel about the same. We are all happy. We (youngster, mother, grandmother and uncle) live together and our world revolves around him."

(Youngster in Sheltered workshop, had been in TAC): "We are more encouraged. He is happy; keeping busy and enjoying work for the most part. The TAC situation he was in last year was not enough. He was unhappy there."

SED/LAP Parent Comments

Although the paucity of numbers of this group precluded our reporting findings separately for the SED/LAP, we felt it was worthwhile to acquaint the reader with the comments of the parent of these youngsters. These parents, whose mentally retarded sons and daughters had been classified in school as LAP (Learning and Adjustment Problems) or, more seriously, SED (Socially and Emotionally Disturbed), often had the most compelling stories. This anecdotal evidence suggests that, at least in some cases, these youngsters have especial difficulty in creating meaningful lives for themselves.

Youngster Not Working Both Years

One SED youngster who has a baby was in an agency program for a few months, but has not been working for two years. Her adoptive mother describes her feelings towards the program:

"I am very frustrated with the system. I felt that the program didn't offer enough supervision. It would give her bus money to get home and to the program the next day. She has no conception of the value of money and would spend it all on the way home. She disappeared one day when school was done and never came home. I called around frantically

and was told by (agency) that the program wasn't responsible for her when she left the premises and that I shouldn't worry because my daughter was a legal adult. It turns out she had left with a male (no one knows who) and now has a severe case of (a sexually transmitted disease) for which she'll need to be hospitalized."

This mother said in 1987:

"I feel that the professionals don't understand the scope of the problem of dealing with these kids and that they are well-intentioned but don't understand the difficulties of day-to-day interaction. I am trying to build my own support group among other parents of special needs kids, and to build a youth group of the youngsters so that they won't miss out on being young and just having fun. I want my daughter to lead as normal a life as possible, but with supervision when appropriate by adults who understand her special needs. I allowed her to use the phone - she ran up an $800 phone bill. She needs supervision - she will shake her own baby and smack her when upset. She is frustrated with the system and says, 'there's no way out for people like me.'"

In 1988, this adopted mother describes herself as more discouraged:

"The situation is much the same but as time goes on the frustration increases, especially with the system. I wish that there were a place where K. could function and be protected. Halfway houses are a hazard. I want K. to have a life and not just be at home but I feel the right environment does not exist for her."

Another youngster, labeled LAP in school, has 3 children and has not had any vocational activity since leaving school. Her mother says:

"I am more discouraged. She seems to be locked into a bad situation of poverty, pregnancies, housing problems. What help she gets come from social workers (DPA). She needs more training, child care help and secure housing before the situation can change."

Youngster in Vocational Situation Both Years

Some of the parents of youngsters who have been in vocational situations for the past two years describe themselves as feeling more discouraged about their youngster's future than they did when he was in school. For these parents, feelings seem related to the youngster's mental problems:

(SED youngster in a WAC for both years' interview)
"I'm worried about him if something happens to me. I resent people being afraid of him. I feel rejected by society because everyone looks askance at me when I am with him. He needs Vocational Rehabilitation to build self-esteem and work possibilities".

(LAP youngster has worked in a restaurant as a dishwasher since 1985, when he began the job as coop student. The young man presently goes in fewer hours a week, as the mother describes it, "he slacks off, doesn't go if he doesn't feel like it.)
"His employer likes him and will not fire him. He sits around and does nothing. He still wants to hit the lottery. He is regressing - more silent and withdrawn. He has mental problems. He was tested and I was told that in his present state there was nothing for him."

Youngster Not Working Last Year, Working This Year

For one LAP youngster at least, however, work seems to have made a real difference in his life. This young man was described in the 1987 interview as being violent and having seizures. Although the marriage was described as being still intact, the wife and 2 younger daughters couldn't handle the violence, so the husband moved out with son. In 1987, the father sounds quite bitter when talking about the situation:

"There was no follow-up or real attempt at job placement by the school. Everything is left up to parent or OVR. In the senior year, the school should work with students to help place them. Students have been sheltered while in school and are lost when they're out of school. They need support and guidance, starting well before they're ready to graduate. My son was in summer job program for 5 years at an office. The office got help for free but wouldn't hire him when he got out. Not supportive."

In the 1988 interview, the son is described as working at an Adult Day Care Center as an attendant with the elderly, placed through a program at CCAC. Father describes himself as more encouraged in this interview:

"He is content; enjoying his work with elderly and youth. I'm happy that he has found something that he likes. He is liked and satisfied."

STUDY SECTION III

ADDITIONAL VARIABLES AND RELATIONSHIPS EXPLORED

ADDITIONAL VARIABLES AND RELATIONSHIPS EXPLORED

The comments of parents whose youngsters we have followed for two years gave us insight into their view of their youngster's situation, past, present and future. There are additional variables explored in these studies which increase our understanding of the ways in which parents view their youngsters' potential for employment and independent living. This section then, will first focus on: the reasons parents of unemployed youngsters gave for their lack of work activity, parents' preferences for youngsters' eventual employment situation, as it relates to their present placement, and parents' preferences for youngsters' eventual living situation, for those parents whose youngsters currently live with them. The discussion will then turn to a number of additional relationships explored in the study; that of in-school vocational training to vocational situation, and of number of parents to vocational situation.

Results discussed in this section are drawn primarily from the three cohorts which were followed for one year: '86 center completers, '87 center completers and '87 mainstreamed completers. Findings from the second year interviews of parents/guardians of the '86 cohort will also be cited, for a perspective on the variables and relationships explored.

Reasons Given for Lack of Work Activity

Parents whose youngsters are not involved in any vocational activity of any kind were asked "Why do you feel he/she is not working at present?". The responses of each group are given below.

TMR group: As can be seen in the table below, the most frequent reasons the parents gave for their youngsters not having an activity were the youngster's attitude and/or behavior, transportation problems, and the need for more training. Additional reasons given include marriage/pregnancy/raising children, disability prevents work, and applied and not called.

EMR group: Parents' answers to this item are given for the total EMR group, and separately for each of the three cohorts - Mainstream completers '87, Center completers '87 and Center completers '86. For the total EMR group, the three most frequent reasons given were youngster's attitude or behavior, primary or secondary disability prevents work, and married/pregnancy/raising children. Additional reasons include transportation problems, problems with the system and needs more training. As can be seen, the reasons given for the youngsters who had been mainstreamed and those who had been educated in the special education centers differ. The most frequent reason given for lack of activity of mainstreamed youngsters is

married/pregnancy/raising children, followed by attitude or behavior, needs more training, and cannot handle work situation. Center youngsters are most frequently described as not working because of their attitude and behavior, their primary or secondary disability, transportation problems and problems with the system.

REASONS GIVEN FOR LACK OF WORK ACTIVITY - TMR (ONE-YEAR)

	CENTER '87	CENTER '86	TOTAL	% (n=16)
Youngster's attitude, behavior	1	2	3	(19)
Transportation problems		3	3	(19)
Needs more training	1	1	2	(13)
Married/children/childbirth/pregnancy	2		2	(13)
Cannot handle work situation		1	1	(6)
Disability prevents work		1	1	(6)
Problems with the system	1		1	(6)
Just finished training	1		1	(6)
Applied, not called	1		1	(6)
Don't know	1		1	(6)

REASONS GIVEN FOR LACK OF WORK ACTIVITY - EMR (ONE-YEAR)

	MAIN-STREAM	CENTER '87	CENTER '86	TOTAL	% (n=31)
Youngster's attitude, behavior	3	3	3	9	(29)
Disability prevents work		3	2	5	(16)
Married/children/childbirth/pregnancy	5			5	(16)
Transportation problems	1	2	1	4	(13)
Problems with the system		2	1	3	(10)
Needs more training	2		1	3	(10)
Cannot handle work situation	2			2	(6)
Employer's attitude			1	1	(3)
Just finished training		1		1	(3)
Incarceration		1		1	(3)
Applied, not called	1			1	(3)
Family's needs precluded those of youngster		1		1	(3)
Don't know		1	1	2	(6)

It is of importance to consider the legitimacy of these reasons in the light of the new approaches to employment that are being touted across the nation and are in evidence locally. Rather than being accepted as immutable barriers to more active lives, the question of whether these factors could be overcome given the new approaches should be carefully considered, along with possible methods to achieve this. This discussion will be enlarged in the issues section.

Parent's Preference for Youngster's Eventual Employment Situation as it Relates to Present Situation

One-year follow-up:

Looking at the table gives us insight into parent preferences for their youngster's eventual employment situation. Parents were asked "What would you prefer your youngster's employment situation to be in 3-5 years?". The table on the next page presents the responses of all the parents interviewed after their youngsters were out of school one year, excluding those of parents of SPMR youngsters. It therefore includes responses of parents of 1986-1987 mainstream completers, 1986-1987 center completers and 1985-1986 center completers.

The findings of this table are very clear. Parents prefer vocationally-oriented activity for their youngsters, and indicate a preference for higher-level placements; i.e. those that more closely reflect real work. Specifically:

* Parents of those youngsters currently in an activity most frequently prefer that type of activity for their youngster.

* The strength of this preference increases as the situation moves toward competitive work: 42% of parents of youngsters in activities centers, 56% of those in sheltered workshops, and 83% of those in competitive employment prefer the status quo.

* The only slight variation is seen in those parents whose youngsters are in supported work, a form of competitive work. Two of the three parents in this position prefer competitive work, one prefers supported work.

* Those parents who do not prefer the status quo, prefer higher level placements for their youngsters. 44% of parents of youngsters in sheltered workshops would like to see them in competitive or supported employment. 53% of parents of youngsters in activity centers express a disinclination for the status quo: 27% would like their youngsters to be in competitive or supported employment, 26% in sheltered workshops.

PARENTS' PREFERENCES BY YOUNGSTER'S PRESENT SITUATION
One-Year and Two-Year Totals (Non-SPMRs)

ONE-YEAR TOTALS (NON-SPMR)

PERCENT OF PARENTS WHO PREFER:	PRESENT SITUATION: NOT WORKING (N=67)	ACTIVITIES CENTER (N=19)	SHELTERED WORKSHOP (N=16)	SUPPORTED WORK (N=3)	COMPETITIVE EMPLOYMENT (N=46)	TOTAL (N=151)
COMPETITIVE EMPLOYMENT	37	11	19	67	83	46
SUPPORTED WORK	24	16	25	33	-	16
SHELTERED WORKSHOP	9	26	56	-	-	13
ACTIVITIES CENTER	4	42	-	-	-	7
OTHER ACTIVITY	9	-	-	-	9	7
STAY AT HOME	6	-	-	-	-	3
NOT SURE OF PREFERENCE	1	5	-	-	7	3
NO ANSWER	9	-	-	-	2	5
TOTAL	100	100	100	100	100	100

SECOND YEAR (NON-SPMR)

PERCENT OF PARENTS WHO PREFER:	PRESENT SITUATION: NOT WORKING (N=21)	ACTIVITIES CENTER (N=14)	SHELTERED WORKSHOP (N=7)	SUPPORTED WORK (N=1)	COMPETITIVE EMPLOYMENT (N=19)	TOTAL (N=62)
COMPETITIVE EMPLOYMENT	33	7	14	100	100	47
SUPPORTED WORK	19	-	-	-	-	6
SHELTERED WORKSHOP	-	21	43	-	-	10
ACTIVITIES CENTER	-	36	-	-	-	8
OTHER ACTIVITY	10	7	14	-	-	6
STAY AT HOME	10	-	-	-	-	3
NOT SURE OF PREFERENCE	-	-	29	-	-	3
NO ANSWER	29	29	-	-	-	16
TOTAL	100	100	100	100	100	100

* 3/4 of the parents of youngsters who are not working or involved in any vocationally-oriented placement would like to see their youngsters in such a placement. They also strongly prefer real work over activity centers or sheltered workshops: 37% would like to see their youngster in competitive employment, 24% in supported employment, 9% in a sheltered workshop and 4% in an activity center.

TMRs: Considering the most impaired youngsters in this group, the TMRs, we find the pattern very similar to that of the total group. Parents most frequently prefer the situation that their youngster is currently involved in, and when they don't, tend to prefer higher level placements. There is, however, somewhat less interest in competitive employment. The parents of the 52 TMR youngsters who do not have a current placement state the following preferences for their eventual vocational situation: 24% supported work, 29% sheltered workshop, 10% activity center, 14% other activity and 10% stay at home.

Two-year follow-up:

The views of the parents of the 1985-1986 who were also interviewed this year can provide insight into the feelings of parents who have lived with their youngsters' post-school situation for an additional year. (See table previous page.) The clearest preference emerges for those parents whose youngsters are in competitive or supported employment. All 20 of these parents (100%) indicate competitive work as their preference for their youngster's vocational situation. Those parents whose youngsters are not involved in any vocational preference also strongly prefer competitive or supported employment for their youngster. 73% of those who state a preference indicate such employment. The parents of youngsters in activities centers and sheltered workshops tend to prefer those situations. The remainder of those whose youngsters are in activity centers prefer sheltered workshops, competitive employment or other activities.

Looking at this cohort in more detail gives us additional perspective. The parents of the 26 EMR youngsters tend to prefer competitive employment for their youngsters, with 20 (77%) stating this preference. (See table next page.) These include the parents of all youngsters currently in competitive or supported employment, and half of those currently idle. The other 50% of those currently idle prefer supported employment. The only parents preferring other options for their children are those with youngsters in sheltered workshops and activities centers who tend to prefer the status quo. The TMR group presents a very different picture. (See table next page.) Half of the parents of youngsters who are not involved in any vocational programming two years post-school appear to have relinquished this possibility, preferring "stay at home" or "other activity" for their youngsters. An additional 13% each

PARENT'S PREFERENCE BY YOUNGSTER'S PRESENT SITUATION
CENTER EMRs - SECOND YEAR

	PRESENT SITUATION					
PERCENT OF PARENTS WHO PREFER:	NOT WORKING (N=6)	ACTIVITIES CENTER (N=2)	SHELTERED WORKSHOP (N=1)	SUPPORTED WORK (N=1)	COMPETITIVE EMPLOYMENT (N=16)	TOTAL (N=26)
COMPETITIVE EMPLOYMENT	50	-	-	100	100	77
SUPPORTED WORK	50	-	-	-	-	12
SHELTERED WORKSHOP	-	-	100	-	-	4
ACTIVITIES CENTER	-	50	-	-	-	4
OTHER ACTIVITY	-	50	-	-	-	4
STAY AT HOME	-	-	-	-	-	-
NOT SURE OF PREFERENCE	-	-	-	-	-	-
NO ANSWER	-	-	-	-	-	-
TOTAL	100	100	100	100	100	100

PARENT'S PREFERENCE BY YOUNGSTER'S PRESENT SITUATION
CENTER TMRs - SECOND YEAR

	PRESENT SITUATION					
PERCENT OF PARENTS WHO PREFER:	NOT WORKING (N=8)	ACTIVITIES CENTER (N=11)	SHELTERED WORKSHOP (N=6)	SUPPORTED WORK (N=0)	COMPETITIVE EMPLOYMENT (N=2)	TOTAL (N=27)
COMPETITIVE EMPLOYMENT	-	9	17		100	15
SUPPORTED WORK	13	-	-		-	4
SHELTERED WORKSHOP	-	27	33		-	19
ACTIVITIES CENTER	-	36	-		-	15
OTHER ACTIVITY	25	-	17		-	11
STAY AT HOME	25	-	-		-	7
NOT SURE OF PREFERENCE	-	-	33		-	7
NO ANSWER	38	27	-		-	22
TOTALS	100	100	100	-	100	100

prefer supported work and sheltered workshop. The preferences of the parents of TMR youngsters in activity centers are: 44% activity center, 22% sheltered workshop, 11% competitive employment, and 22% no answer. Of parents whose youngsters are in sheltered workshops, 29% each prefer that placement, and are not sure of their preference and 14% each prefer competitive employment and other activity.

Parents' Preference for Youngsters' Living Arrangement

One-year follow-up:

The former students investigated in this study live overwhelmingly with their parents. 83% of the total one-year group (123 of 148) live with their parents or guardians: 84% of special education center completers, and 80% of those who were mainstreamed. How do their parents and guardians feel about this? Do they see this as a permanent situation? Does this reflect their ultimate preference?

In order to explore these issues, parents were asked "What would you prefer your youngster's living arrangement to be in 3-5 years?". The response categories were: living with parents/guardian, living in a CLA (Community Living Arrangement), supervised apartment, group setting, living independently with friend or roommate, living independently with spouse, living alone, living in a residential institution and other. The table on the next page presents the results of this question for parents whose youngsters live with them. It includes the responses for all non-SPMR youngsters.

The parents of center completers strongly prefer their youngsters to remain with them, with 67% expressing this desire. An additional 13% would like to see their youngster eventually living independently, 12% would prefer their youngster to be living in a group setting. It should be noted that the parents of TMR youngsters, the most severely impaired of this group, express the preference for their youngsters living with them even more strongly (see table next page.) At present 86% of TMR youngsters live with their parents or guardians. Of these, a full 80% would prefer their youngster to remain with them, 18% would like to see them in a group setting and 2% living independently. The preferences of the parents whose mainstreamed youngsters live with them show a different pattern. Only 38% prefer their youngsters to remain with them, an additional 38% would like to see them living independently, and 4% prefer a group setting of some kind for their youngsters.

LIVING ARRANGEMENT PREFERENCES OF PARENTS WHOSE YOUNGSTERS LIVE WITH THEM

NUMBER OF PARENTS WHO PREFER:	ALL CENTER COMPLETERS #	(%)	MAINSTREAMED COMPLETERS #	(%)	TOTAL GROUP #	ONE-YEAR (NON-SPMR) (%)
Independent	13	(13)	9	(38)	22	(18)
Parent/Guardian	66	(67)	9	(38)	75	(61)
Group Setting	12	(12)	1	(4)	13	(11)
Not Specified/No Answer	8	(8)	5	(21)	13	(11)
TOTAL	99	(100)	24	(100)	123	(100)

LIVING ARRANGEMENT PREFERENCES OF PARENTS
OF YOUNGSTERS WHO LIVE WITH THEIR PARENTS
TMRs After One Year

PARENTS' PREFERENCE	#	(%)
With Parent/Guardian	35	(80)
In Group Setting	8	(18)
Alone	1	(2)
TOTAL	44	(100)

(44 = 86% OF TOTAL)

LIVING ARRANGEMENT PREFERENCES OF PARENTS OF YOUNGSTERS WHO LIVE WITH THEIR PARENTS

Non-SPMRs (Second Year)

PARENTS' PREFERENCE:	#	(%)
Independent	4	(9)
Parent/Guardian	31	(66)
Group setting	3	(6)
Not specified/no answer	9	(19)
	47	(100)

LIVING ARRANGEMENT PREFERENCES OF PARENTS OF YOUNGSTERS WHO LIVE WITH THEIR PARENTS

TMRs (Second Year)

PARENTS' PREFERENCE	#	(%)
With Parent/Guardian	19	(86)
In Group Setting	1	(5)
Not specified/no answer	2	(9)
TOTAL	22	(100)

(22 = 81% OF TOTAL)

Two-year follow-up:

The views of the parents of 1985-1986 completers whose youngsters continue to live with them help to indicate whether these preferences change over time. 76% of the non-SPMR school completers of this center cohort continue to live with parents/guardians. (See table previous page.) 66% of these parents state that they prefer their youngsters to be living with them in 3-5 years, almost identical to the 67% of parents of the comparable 1986-1987 cohort expressing this view. An additional 9% would like to see their youngsters in an independent living arrangement, 6% in a group situation. Focusing on the more impaired, TMR 1985-1986 completers, we find that 81% of these youngsters remain at home two years after they have finished school, the same percent as in the 1986-1987 group. 86% of the parents of these youngsters prefer that their youngsters remain with them, a higher percent that the 80% found in the one-year following-up above. (See table previous page.) 5% prefer a group setting for their sons or daughters.

Parents' and guardians' preference for their mentally retarded youngsters to remain with them appears quite strong, and is not diminished after two years. It is even more pronounced among parents of TMR youngsters. The only group of parents who appear willing to consider independent living on an equal basis is the parents of the least impaired EMR youngsters, those whose schooling took place in mainstreamed settings.

As will be discussed in the issues section of this report, this preference for youngsters remaining at home raises concern. Is this a realistic long-term alternative and what are the likely effects on parents and youngsters? Should there, and can there, be efforts made to encourage parents to consider alternative living arrangements for their youngsters? (Note: even with 67% of parents of 1986-1987 center completers preferring their youngster to remain with them, there are 25% who would prefer an independent or group setting. Maybe the place to start is with them.)

Relationship of Present Situation to In-School Vocational Training: Does In-School Vocational Training Make a Difference?

One of the important questions of this research is whether the vocational training these mentally retarded youngsters receive in school makes a difference. Are youngsters with more advanced training more likely to be working? Are they working in the fields for which they trained? As was seen in previous research under the auspices of the Trees Trust (Gordon and Zamule, 1986) much of the curriculum for the center-based youngsters is vocational. They typically spend much of their high school-level education in prevocational and vocational

courses in such fields as distributive education (retailing), food service, auto mechanics, building and grounds maintenance and carpentry. More impaired youngsters, which includes almost all TMRs and some EMRs, often spend half of their days, for a number of years, in Work Activity Centers (WACs) developed to closely resemble post-school WAC programs. Additional vocational possibilities for center-based youngsters include cooperative work, in which youngsters are supervised for half-day placements at real work settings, and programs at Area Vocational-Technical Schools (AVTS) which offer more advanced courses in fields such as appliance repair, baking, warehousing and meatcutting. Mainstreamed youngsters may participate in vocational courses at the special centers, in cooperative education, and in courses at the AVTSs. In addition, youngsters may take training courses when they finish school. Typical courses in this area, developed for special populations, involve training for food service, janitorial, and health aide positions.

The present study, exploring whether in-school vocational training makes a difference looked at the relationship between training and the present vocational situations of study subjects. In considering these findings, it should be kept in mind that the more able youngsters are more likely to have had more advanced vocational experience such as coop work and AVTS training, and that it is not possible to separate out the effects of ability, and of level of training, on work status.

Each individual was rated according to the highest level of in-school vocational training he/she had received. The values of this variable were: none, WAC only, center-based vocational courses, coop work, and AVTS. We looked at the relationship of this variable with present vocational situation.

<u>One-year follow-up</u>

The tables presenting the one-year follow-up indicate this relationship for center-based EMR's, mainstreamed EMRs and TMRs.

Center-based EMR's: This table indicates the complexity of the situation. (See table next page.) Looking at the employed column, we see that the highest level of vocational training of those who are employed one-year after finishing school, is, in order of frequency, co-op placement (46%), AVTS (39%) and in-school vocational courses (14%). However, when we look at the levels achieved by those who are currently idle, we see a very similar breakdown of vocational level: co-op placement (46%), AVTS (21%), vocational courses (33%). Looking at this from another perspective, of those 25 individuals whose highest level of vocational training was co-op, 52% are working, but 44% are idle. For AVTS, 61% are working, 28% are idle and 11% are in training. In terms of the remainder of the table: those currently in training all reached AVTS level; those in sheltered workshops tend to have had vocational courses at the centers or to have been in WACs; those in activity centers, are equally likely to have been in WACs only, to have had vocational courses

SUMMARY OF PRESENT SITUATIONS BY VOCATIONAL EXPERIENCE - ALL CENTER EMRs (ONE-YEAR)

Vocational Training	IDLE #	(%)	ACTIVITIES CENTER #	(%)	SHELTERED WORKSHOP #	(%)	EMPLOYMENT #	(%)	TRAINING #	(%)	TOTAL #	(%)
WAC only	-	-	1	(33)	1	(20)	-	-	-	-	2	(3)
Vocational Courses	8	(33)	1	(33)	4	(80)	4	(14)	-	-	17	(27)
Co-op Placement	11	(46)	1	(33)	-	-	13	(46)	-	-	25	(40)
AVTS Training	5	(21)		-	-	-	11	(39)	2	(100)	18	(29)
	24	(100)	3	(100)	5	(100)	28	(100)	2	(100)	62	(100)

SUMMARY OF PRESENT SITUATIONS BY VOCATIONAL EXPERIENCE - MAINSTREAM 1987

Vocational Training	IDLE #	(%)	ACTIVITIES CENTER #	(%)	SHELTERED WORKSHOP #	(%)	EMPLOYMENT #	(%)	TRAINING #	(%)	TOTAL #	(%)
None	2	(25)					4	(24)	2	(40)	8	(27)
Vocational Courses	2	(25)					4	(24)			6	(20)
Co-op Placement	1	(13)					1	(6)	1	(20)	3	(10)
AVTS Training	3	(38)					8	(47)	2	(40)	13	(43)
	8	(100)	-		-		17	(100)	5	(100)	30	(100)

and to have had co-op placements.

In order to further explore whether having had an AVTS course or a co-op placement differentiated present vocational status, we conducted chi square analysis based on these two variables. In looking at this for co-op placement, we included those who had had both co-op and AVTS experience, and so would be appear in the AVTS column of the table. Both of these analyses approached, but did not reach, significance. However, when these vocational experiences were put together, so that all youngsters who had had AVTS or coop were in one group, the relationship with employed/not employed was found to be significant ($p<.01$). It appears the EMR youngsters at the centers who have had co-op or AVTS experience, or both, have a better chance of being employed one year after school than those who have had either of these. As was mentioned above, however, in considering this finding it must kept in mind that it is the more able youngsters who are chosen for coop and AVTS placements. It is therefore not possible to determine the extent to which these youngsters' increased likelihood of working is due to their greater ability, and to their exposure to these training experiences. It is likely a combination of both that enhances their vocational potential.

JOB SITUATION BY AVTS OR CO-OP EXPERIENCE
All Center EMRs after One Year

	No Co-op or AVTS		With Co-op or AVTS		TOTAL	
	#	%	#	%	#	%
Without Job	14	(78)	18	(43)	32	(53)
With Job	4	(22)	24	(57)	28	(47)
TOTAL	18	(100)	42	(100)	60	(100)

Mainstreamed EMRs: This table indicates the highest vocational level reached by those employed to be: AVTS (47%), co-op (6%), vocational courses (24%), and none (24%). (See table previous page.) The highest vocational level reached by those currently idle is shown as: AVTS (38%), co-op (13%), vocational courses (25%), and none (25%). One finding that is noticeable is that of 13 individuals who reached an AVTS, 8 (62%) are currently working, 3 (23%) are idle and 2 (15%) are in training, suggesting a role for AVTS. However, again, in chi square analysis, the relationship of AVTS attendance alone on employment status approached, but did not reach, significance. In terms of the remainder of the table, the youngsters in training have

backgrounds that include AVTS, co-op or no in-school vocational training.

TMRs: The TMR youngsters show a very different pattern of post-school placement and vocational experience. (See table next page.) The most common vocational situation one-year after school, for 20 out of 52 youngsters, 38%, is idleness. The next most common, for 31%, is an activity center. Half of the TMR youngsters had WAC only while in school, none attended an AVTS. There is again, no clear relationship between these variables. Of those individuals who only had WAC placement, 42% are idle, 35% are in activity centers and 23% are in sheltered workshops. Those who reached the level of vocational courses are about as likely to be idle (41%) as to be in an activity center or sheltered workshop (48%). The only suggested relationship with vocational status is that of co-op placement. Of the few TMRs who reached this level, 5 out of the 7 are to be found in sheltered workshops or employed (71%), 2 (28%) are idle.

SUMMARY OF PRESENT SITUATIONS BY VOCATIONAL EXPERIENCE - ALL TMRs (ONE YEAR)

Vocational Training	IDLE #	(%)	ACTIVITIES CENTER #	(%)	SHELTERED WORKSHOP #	(%)	EMPLOYMENT #	(%)	TRAINING #	(%)	TOTAL #	(%)
None	-	-	2	(13)	-	-	-	-	-	-	2	(4)
WAC only	11	(55)	9	(56)	6	(50)	-	-	-	-	26	(50)
Vocational Courses	7	(35)	5	(31)	3	(25)	1	(33)	1	(100)	17	(33)
Co-op Placement	2	(10)	-	-	3	(25)	2	(67)	-	-	7	(13)
	20	(100)	16	(100)	12	(100)	3	(100)	1	(100)	52	(100)

Two-year follow-up:

The results from the two-year follow-up on this variable can help indicate whether the effects of in-school vocational training are long-term; whether there is a relationship between training level reached and vocational placement two years after leaving school.

SUMMARY OF PRESENT SITUATIONS BY VOCATIONAL EXPERIENCE
CENTER EMRs - SECOND YEAR

Vocational Training	IDLE	ACTIVITIES CENTER	SHELTERED WORKSHOP	EMPLOYMENT	TOTAL
WAC only		1			1
Vocational Courses	4		1	2	7
Co-op Placement	1	1		6	8
AVTS Training	1			9	10
TOTAL	6	2	1	17	26

It appears that those EMRs who reached higher levels of training are more likely to be employed two years after leaving school. (See table above.) By their second year out of school, 9 out of the 10 youngsters in this cohort who reached the AVTS level, and 6 out of 8 who reached co-op level, are employed. Of those who only reached the level of vocational courses, 4 out of 7 are idle, 2 are employed and 1 is in a sheltered workshop. In testing this relationship by chi square analysis, the group was divided into employed and not employed. Not employed included the idle, activities center, training, and sheltered workshop categories. The other variable in the relationship was vocational training, divided into 3 groups: WAC and vocational courses, co-op placement, and AVTS training. A significant chi square ($p < .025$) was found for this relationship. Looking at the table below, indicates that, for this cohort, those youngsters reaching higher levels of vocational training are more likely to be employed. Again, the proviso regarding the confounding of ability with training opportunity holds, and it is likely a combination of the two that increases probability of working.

VOCATIONAL BACKGROUND OF THOSE WITH OR WITHOUT A JOB
Center EMRs - Second Year

Vocational Training	NO JOB	WITH JOB	TOTAL
WAC, Vocational Courses	6	2	8
Co-op Placement	2	6	8
AVTS Training	1	9	10
TOTAL	9	17	26

The second year follow-up of the TMRs show them to be: in activity centers (41%), idle (30%), in sheltered workshops (22%) and employed (7%). (See table below.) The only relationship suggested in the table is that between activity center and WAC: 63% of those in activity centers had only WAC in school, and 58% of those who had had WAC only wound up in activity centers.

SUMMARY OF PRESENT SITUATIONS BY VOCATIONAL EXPERIENCE
CENTER TMRs - SECOND YEAR

Vocational Training	IDLE	ACTIVITIES CENTER	SHELTERED WORKSHOP	EMPLOYMENT	TOTAL
None		2			2
WAC only	3	7	2		12
Vocational Courses	3	2	2	1	8
Co-op Placement	2		2	1	5
TOTAL	8	11	6	2	27

Matches Between Field of Employment and Previous Training

A question pertaining to the relationship of employment and vocational training is whether youngsters are employed in the fields in which they were trained. In attempting to answer this, we looked at those youngsters who are presently employed and determined whether the type of work done matched any of the individual's previously training experiences. In searching for such matches we considered post-school, along with in-school, training experiences. In the 1985-1986 cohort interviewed last year, we found 2 such matches of job to training: a mechanic who had taken auto mechanics at his school and a maintenance man who had taken buildings/grounds maintenance in school. The 1986-1987 cohort interviewed this year proved to have a greater number of matches. 8 out of the 13 employed EMR center completers (out of

a total of 34 completers) held a job in an area in which they had received some kind of training. The matches were:

* 3 restaurant workers who had taken Food Service at a center and had been placed in coop jobs in this field. The coop jobs continued as their present positions.

* A restaurant worker who had had a coop job in this field.

* A nurse's aide who had had AVTS and coop experience in the field. The coop job became permanent.

* A meatcutter who had taken an AVTS meatcutting course.

* A janitor who had had both a course at his center and post-school training in the field.

* A janitor who had had post-school janitorial training.

Four mainstream completers, out of 17 working and a total of 30, are holding jobs which match elements of their past training. These individual are:

* A messenger at a graphic arts store who had taken Graphic Arts at a center.

* An electrical apprentice who had had a relevant course at an AVTS.

* A restaurant worker who had had both a center course and coop experience in food service.

* A restaurant worker who had taken a post-school training course.

Thus, some youngsters do manage to obtain jobs in fields in which they were trained, and numbers this year are greater than last year. Each of these cases is heartwarming and important. However is this enough given the great emphasis on vocational training in these youngsters' school careers? We have just discussed the 12 EMR 1987 completers who are in jobs that match an element of their vocational training. 55 of the 64 1987 EMR completers (center and mainstream) spent years in a variety of vocational courses. That means that only 22% (12/55) of youngsters who have had vocational training found jobs that related to some aspect of that training.

Relationship of Number of Parents to Employment Status

An additional finding of interest will be presented. Among the few significant relationships found in this study is the

relationship of number of parents to employment status. Simply put, for the group of '87 EMR completers, composed of both center and mainstreamed students, those who come from 2-parent families are more likely to be employed than those who come from one-parent families ($p<.05$). 57% of those with two parents have jobs, compared with 33% of those with one parent. 67% of those with one parent, and 43% of those with two parents, are not working. Put another way, 38 out of 45 employed EMR completers, 84%, come from two-parent families. (See below.)

WORK SITUATION OF EMRs BY NUMBER OF PARENTS
1986 and 1987 Cohorts (One-Year)

	One Parent	Two Parents	Total
No Job	14	29	43
Job	7	38	45
TOTAL	21	67	88

This finding proved difficult to explain. All the obvious explanations did not hold up when tested. This relationship proved not to be explained by differences between the two types of families that might have been expected. Tested for significance were: SES, education of parents, total number of children, number of children living at home, and income. Lower incomes proved more likely for the one-parent families (with 90% of 1-parent families, and 56% of 2-parent families, earning <$25,000) but this did not have a relationship with employment status.

It is intriguing to speculate on explanations for this finding. Possibilities come to mind which are not testable in this study. Perhaps one-parent, primarily female-headed, families:

* have fewer resources to expend on negotiating the systems that are necessary to obtain employment for a handicapped youngster.

* have fewer contacts in the job world that might pay off in work for a son or daughter.

* are more reluctant to send a youngster to work; are more overprotective.

* have more difficult youngsters, whose problems helped to break up the marriage.

* tend to be older, since death of spouse is one cause of one-parent families.

For the purposes of this study, these must remain speculation. They can, however, suggest future directions for research. This finding does suggest, however, that this is an area in which special efforts to assist one-parent families would be well advised, as outcomes for handicapped children from these families are likely be less positive than those for children from intact families.

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